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ABSTRACT

To develop a definition and guidelines for the establishment of a model statewide advocacy program, a multilevel survey consisting of questionnaires, telephone interviews, and personal interviews was conducted with developmentally disabled individuals, members of direct service and administrative agencies, and community board members. A literature review on the term advocate and past and present advocacy efforts was initiated. Data was broken down into nine areas: definition of advocacy, goals of advocacy, differences between advocacy and protective services, service categories in which advocacy services are most needed, developmentally disabled client groups most in need of advocacy services, optimum administrative location for advocacy programs, funding sources for advocacy programs for the developmentally disabled, problems to be anticipated in initiating and maintaining an advocacy program, and training. Among findings were that the perceived objectives and goals of an advocacy service were vague and that many people see the potential positive value of a responsible advocacy program as a monitoring device. (Sample questionnaires are appended.) (SBH)

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DEVELOPMENTAL DISABILITIES ADVOCACY PROJECT

Dr. Adrian Chan
Mr. Michael C. Brophy
Mr. Patrick Garland
Mr. Patrick Linnane
Ms. Rozanne Screven

Office of Research
School of Education
University of Wisconsin - Milwaukee

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FINAL REPORT

February 1, 1976

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I.

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AC,MB,PG,PL,RS
February 1, 1976

II.

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II.

SUMMARY OF FINDINGS

This Developmental Disabilities Advocacy Project was funded by the Wisconsin Council on Developmental Disabilities to develop a definition and guidelines for the establishment of a model state-wide advocacy program. A multilevel survey consisting of questionnaires, telephone interviews and personal interviews was conducted a) in Wisconsin with developmentally disabled individuals, volunteer and professional direct service agency personnel, community board members and administrative agency members, and b) in Washington, D.C. with members of national agencies and legislative personnel related to this area.

A brief view of our efforts reflect the following:

--There is no definition of advocacy which emerges with anything close to a concensus from all of the respondents. Concrete examples tended toward protecting, benevolent kinds of activities in which the advocate was perceived as doing something for the developmentally disabled person with only minimum concern for client participation in the decision making or implementation processes.

--Consistent with the lack of definition, the perceived objectives and goals of an advocacy service were vague. Few respondents had a clear perspective on a "least restrictive" environment as it pertains to the developmentally disabled citizen. The largest number of respondents emphasized the protection of rights for the developmentally disabled. Very few respondents associated "least restrictive" with the maximization of responsible self-assertiveness and independence for the developmentally disabled person.

--Advocacy was associated with socio-legal and protective services. It was seen in a broader, more informal context than either of the other two related concepts.

--Some respondents saw the advocacy function as potentially threatening to the stability of already established and essential services.

--Some respondents indicated that a positive advocacy program might serve the purpose of effectively reaching out to and/or attracting developmentally disabled citizens not already being served.

--Virtually all respondents agreed that an advocacy program should be an independent entity and as free as possible from pressures which might be brought to bear by special interest groups.

--A great deal of pessimism emerged from all respondents regarding possible funding sources for advocacy programs. There was more interest on the national and state levels than on the county or community levels.

--Many persons doubted that the right kind of person could be hired, trained and maintained as an advocate for a long enough period for them to be effective. Problems mentioned included conflicts of interest between career ambitions and advocacy responsibilities, the advocacy process and the interests of institutions and agencies impacted, and the accessibility of the necessary accurate and up-to-date information from relevant institutions and agencies.

--All respondents indicated the necessity of an advocacy training program preceeding the implementation of an advocacy program. Training should include emphasis on communication skills, evaluation, understanding the system, understanding the developmentally disabled person, coordination with other advocacy programs and community relations.

--In conclusion, many persons saw the potential positive value of a responsible advocacy program as a monitoring device. They felt that such a program could serve the clients and the institutions and agencies involved by obtaining better service, promoting better policies and ensuring delivery of promised services.

Results from the survey (Wisconsin and Washington, D.C.), coupled with a literature review and much staff discussions, led to the development of a definition of advocacy and a multiple advocacy model by which to view all other existing advocacy efforts. Recommendations were made as to the incorporation of this multiple advocacy model in the state-wide advocacy program for fiscal years, 1976 and 1977. In short, for fiscal year 1976, the staff saw the need for a) the development of training and evaluation materials in multiple advocacy roles for various people in this arena, b) th implementation of multiple advocacy training and evaluation procedures, and c) the coordination and unification of existing advocac efforts in developmental disabilities. Fiscal year 1977 recommendations were also made.

INTRODUCTION

A. Review of Objectives

The Developmental Disabilities Advocacy Project was funded $19,978.84 by the Wisconsin Council on Developmental Disabilities to develop a definition of advocacy and guidelines for the establishment of a model state-wide advocacy program. The project began in June of 1975 and was completed in January of 1976. The ultimate source for these funds was made possible by the Developmental Disabilities Services & Facilities Construction Act, Public Law 91-517. The objectives and sub-objectives of this project were as follows:

Objective # 1 -- To develop a definition and guidelines for the establishment of an advocacy program for the developmentally disabled. This includes:

a. A literature review of the problem area

b. Contacting voluntary state developmental disabilities groups, the Task Committee on Health & Social Services, the Wisconsin Nursing Home Ombudsman Program, the State Consumer Protection Agency, the Health Policy Council, (51.42 & 51.437 Boards, DVR counselors);

c. Contacting other national groups in this area.

Objective # 2 -- To develop a model of an advocacy program based upon the information obtained which includes, at minimum, system advocacy and personal advocacy. This model should:

a. Specify the essential elements of each of a number of alternative advocacy programs, their advantages-disadvantages, their estimated costs specify key elements of system versus personal advocacy programs, their similarities-differences, advantages-disadvantages;

b. Provide suggestions on how advocacy services and individual advocates should be evaluated

c. Recommend roles and interrelationships of voluntary organizations, community boards in advocacy programs with other organizations and agencies;

d. Define the relative merits of public versus private administration, local-regional-state organization, generic versus developmental disabilities approaches, to advocacy programs and recommend sources of public/private, local-state-federal funding of these programs.

The project called for 1) examination of various theories and practices of advocacy, 2) making judgments about these theories and practices, 3) developing a model of advocacy, 4) suggesting guidelines for the establishment of future advocacy programs, and 5) recommending roles and interrelationships of local, regional and state units in the facilitation, funding and evaluation of advocacy programs for the developmentally disabled.

B. Review of Literature

A Brief History of the Term "Advocate". The term "advocate" derives from the Latin advocare (Latin Dictionary for Schools. Carlton T. Lewis, Ph.D., Oxford - at the Clarendon Press, 1901, p. 40). As with so many English-American words derived from Latin, the meaning of "advocate" has changed slightly but significantly. The change is particularly significant when one considers the possibility of developing and initiating a program which would purport to advocate for developmentally disabled citizens or others.

Initially, the term meant "friends and supporters" and was used to designate even those who might not be friends and supporters but only potential helpers or assistants. Cicero, a famous Roman orator, born in 133 B.C., used the term to indicate "friends and supporters", "amici advocatique" (Cicero, Pro Caecina, chapter 8). It is also interesting to note that in the introduction by the translator, H. Grose Hodge, Cicero is called an advocate (page 4). This translation was made in 1927. Cicero, an Equestrian by birth and a Roman Senator by elevation, certainly fits the current English-American understanding of what an advocate is, in so much as it was his wont to utilize his considerable resources and skills as an orator to help the overtaxed and non-represented provincials who were being persecuted by fellow members of the Equestrian Order.

Titus Livius, known as Livy, another famous orator who was born in 59 B.C., in his history of Rome entitled "From the Founding of the City", used the term advocatis to indicate "those he had called to his assistance" (Livy, Book 2, Chapter 55, translation by B.O. Foster, p. 405).

Since that time, the term, in Western Civilization, has come to have a much more formal meaning. For example, in the Dutch language, the term advocaat means lawyer. In England and America, the term "advocate" appears to fall just short of meaning only one who is certified to practice before the bar in a formal court of law. For example, in Gitlow v., People of the State of New York, 69 L.Ed. 1145, the supreme court defined "advocacy" as follows: "Advocacy is defined in the Century Dictionary as: 1. The act of pleading for, supporting, or recommending; active espousal." In another court decision, Ex parte Bernat, D.C. Wash., 255 F. 249, 432, "advocate" has been defined as follows: "'Advocate' means to speak in favor of defend by argument, one who espouses, defends, or vindicates any cause by argument, a pleader, upholder, as an 'advocate' of the oppressed, and may be done as well through written communications, personal direction, through the public press, or through any means by which information may be disseminated, or it may be done by the adoption of sentiment expressed or arguments made by others which are distributed to others for their adoption and guidance."

Webster's Third New International Dictionary (1971) at p. 32 defines "advocate" as: "1. one that pleads the cause of another" and gives as examples the following: "we have an advocate with the Father, Jesus Christ---1 Jn 2:1"; "accepted the responsibility of acting as a personal advocate for his chief"; "2. one that argues for, defends, maintains, or recommends a cause or proposal; for example, his warmest advocates agree in this with his severest critics"; "the advocates of classical education". The term "advocacy" in the same source is defined as "1. the profession or work of an advocate 2. the action of advocating, pleading for, or supporting: for example, "devoting a lifetime to the advocacy of economic reforms", or "a consequence of his moving advocacy."

Current usage of the terms "advocate" or "advocacy" is common. For example, "Church activism has ebbed in recent years, after flourishing in the crisis-filled sixties, but its advocates still pursue an array of old and new issues with an ethical passion that angers many of their fellow Christians." (New York Times, Sunday, January 11, 1976, section 4, p. 20) and "In its advocacy of Western Europe's 'invisible men' and its linking of text and photographic image, 'A Seventh Man' invites comparison with 'Let Us Now Praise Famous Men', that minor American classic of the 1930's by James Agee and the photographer Walker Evens." (New York Times Book Review, January 11, 1976, p. 19). The "invisible men" referred to in the above quotation are the migrant workers of modern Western Europe whose position in that social order is similar to the provincials of Cicero's time.

It is evident that the term "advocate" as well as the term "advocacy", indicating the function of an advocate, has undergone a slight but significant change from its original meaning in Latin. Originally the meaning was less formal indicating friendship or assistance of any kind. The present meaning of the term encompasses that of the past but would appear to include passionate commitment up to the point of verbal, written, and/or graphic confrontation. Modern English-American usage of the terms also implies the utilization by the advocate of substantial skills and resources in the process of advocacy. It is certainly identified in part with the adversary system of practicing law by certified attorneys.

In an educational and therapeutic context, the term is often misunderstood because of this identification with adversary proceedings and potential confrontation. This has occurred in many areas because of the tendency on the part of those who would call themselves advocates for children, the aging, the developmentally disabled, etc. to allow themselves to be identified primarily with what they are against rather than what they are for. This will certainly be a problem for any program or persons which presume to function under the label of "advocate" or "advocacy". Many programs and/or persons who presently function under the rubric of advocate or advocacy emphasize the negative or threatening nature of their role as opposed to their intentions regarding the positive nature of their impact upon individual behavior and institutional change.

Current Status of Advocacy. Although the concepts, "advocacy" and "advocate" can be traced back to ancient Roman writings and early Roman Catholic church law, it has only been in recent years that these concepts have gained in popularity across many segments of the human services professions. Advocacy efforts can be found cutting across different age groups, such as the National Center for Child Advocacy (Office of Child Development, Department of Health, Education and Welfare), Parent ACT (Advocates for Children Today) in Milwaukee, Youth Advocates and Senior Advocates (in Seattle, Washington), Nebraska Youth Advocate, and advocacy and ombudsman programs for the elderly. Such efforts also transcend radically different client groups and problem areas. Examples include: Consumer Advocates (a la Ralph Nader), Welfare Advocacy

Center in Milwaukee, Nursing Home Advocacy-Ombudsman Programs, Citizen Advocacy, Association for Retarded Citizens, Epilepsy Foundation, Developmental Disabilities Advocacy Program, United Cerebral Palsy advocacy efforts, etc.

All of these advocacy approaches seem to emphasize a common set of activities within an intervention-service framework. They provide guidance and/or perform some instrumental or emotional service on behalf of the individuals with the assumption that these individuals are physically, mentally and/or social-psychologically incapable of performing such services themselves. A general survey of recent literature does not change this present perception of advocacy. Such writings include: a) Adams, Berg, Berger et al, Children's Rights (1972), b) issues of Harvard Educational Review (1972,1973), c) Kahn, Kamerman & McGowan, Child Advocacy (1973), d) National Commission on Resources for Youth, New Roles for Youth (1974), and e) Wolfensberger, Citizen Advocacy for the Handicapped, Impaired & Disadvantaged: An Overview (1972). Critical examination of these and other related writings indicate some tendency of thinkers to move toward a conceptual framework (e.g., Wolfensberger's Citizen Advocacy model). However, there is little systematic empirical research of any rigor to indicate its construct validity or conditions for success/failure nor are there studies comparing various advocacy approaches with other similar approaches. It is interesting to note that as the concept of advocacy gains in popularity, commensurate with funding, conceptual writing and empirical research have not increased in the same magnitude. With so many different advocacy efforts currently under way, there is little to distinguish an advocacy program from a non-advocacy program.

Developmental Disabilities and Advocacy. Advocacy for the developmentally disabled does not differ from the current status of advocacy in other human service areas. This is substantiated by the Proceedings from the National Conference on Initiative Functions of Developmental Disabilities Councils held in Winter Park, Colorado, June 11-14, 1974 as found in Advocacy: A Role for DD Councils (edited by J.L. Paul, R. Wiegerink & G.R. Neufeld). Here in Wisconsin, much of the advocacy efforts for the developmentally sidabled is implemented via a) the Protective Services Act (2 Wis. Leg. Serv. '74, Ch. 284, see also 1975 Wisc. Assemb. Bill 573, b) the Developmental Disabilities Services & Facilities Construction Act, P.L. 91-517, and c) the new Developmentally Disabled Assistance & Bill of Rights Act, P.L. 94-103. A sampling of advocacy efforts for the developmentally disabled operating within Wisconsin reveal the following: a) Citizen Advocacy, via the United Association for Retarded Citizens, b) the Wisconsin Association for Retarded Citizens, c) the now-defunct Developmental Disabilities Advocacy Program, and d) the United Cerebral Palsy advocacy efforts.

What is needed is a more careful examination of the different programs which function under the rubric of advocacy and protective services so that some common framework can be developed to add clarity and to make distinctions regarding their direction and goals. There are presently some advocacy approaches which can be classified as models or conceptual frameworks. Models exist which emphasize a person advocating for or on behalf of the client (the most common type) versus someone teaching/guiding the client how to advocate on his/her own behalf (i.e., the Advocate Counseling Model of Brophy, Chan, Mar & Nagel). System advocacy models, focusing on legal and protective services, exist along with personal advocacy models, focusing on helping the client's daily needs. Wolfensberger (1972) cites many other types of advocacy - generic advocacy, collective/corporate advocacy, group advocacy, multiple advocacy, dispersed advocacy, crisis advocacy, youth advocacy and advocate associate.

Whether we are talking about advocacy as a one to one relationship or as a system approach we find little coordination or agreement between the advocacy groups. They would seem to be working as autonomous organizations with varying philosophies and goals. They range in scope from several neighborhood people attempting to help a single individual to large organizations which engage in both individual and system advocacy. The methodology is as varied as the organizations. Group "sit ins" is defined as advocacy as well as the acquisition of a lawyer to "advocate" in court. We find that some groups "advocate" for themselves while other groups "advocate" for others.

Because of this multitude of approaches and philosophies, there exists a duplication of efforts. The groups who advocate in the area of developmental disabilities advocate for individuals of all ages, ethnic and economic backgrounds. As a result, we find that the individual who, for example, may be retarded is conceivable the potential recipient of the same services from advocates for the aged, welfare advocates, lawyer advocates, citizen advocates and ombudsmen, as well as developmental disabilities advocates. This may, in some instances, benefit the individual but the confusion that exists in the advocacy area, along with the demise of various advocacy programs would indicate a need for greater coordination, clarity of roles and communication among the various organizations.

At the present time, it would appear that advocacy, for all of its forms, is still embrionic. Questions of the most basic nature are still being raised. Should advocates be a part of the institution in which they advocate or can they better serve from without? Are they "doers" or "teachers"? Are they a volunteer or a professional? Should they be expert in their field of advocacy or just concerned people? There is a glaring lack of goals aside from the all too familiar ones of normalcy, rights, dignity, etc. which can become meaningless unless defined, made explicit and formalized.

On a more positive note, we do find an interest in advocacy and a commitment on the part of many people. Not all agree on what advocacy is but there is a definite interest and commitment on the part of many to do something for either themselves or others. The BEH/NIMH/RSA Child Advocacy Grants (1972) reveal that minorities are being introduced to advocacy through neighborhood organizations as well as volunteer professional minority people with access to institutional "ears" serving as an articulate voice.

Our literature search indicates that the most active advocacy programs exist in the Association for Retarded Citizens. The "Association", on the local levels, practices both individual and system advocacy. The individual advocacy is similar to that described by Wolfensberger. The A.R.C. recruits a volunteer and pairs him/her with a protegè, i.e., client, and this volunteer citizen advocate helps the protégè in his instrumental and expressive (emotional) needs.

The A.R.C.s also bring pressure to bear as a group, through the appropriate channels, for the retarded individuals as a group. In general, they insist that the disabled individual be given the rights and privileges of non-disabled citizens.

Associations representing the needs of the cerebral palsied and epileptic also have advocacy programs in various parts of the country but lack the overall organization and effectiveness of the A.R.C.s. In Southeastern Wisconsin, for example, advocacy efforts were made by both the United Cerebral Palsy Association and the Epilepsy League. Both met with something less than success and are no longer in existance. Lack of funds, foresight, organization, leadership and public relations were among the reasons that contributed to the demise of these efforts. These failures have resulted in cynicism and doubt on the part of some concerning the funding and effectiveness of advocacy efforts in these areas in particular and advocacy in general.

The impression should not be left that these Milwaukee experiences are universal. The United Cerebral Palsy Association in New York City continued its advocacy efforts in much the same area as was attempted here. The thrust of this advocacy effort aimed at the assistance for children to obtain needed services. The data collected in these efforts is earmarked for use in pushing for needed legislation, as indicated in BEH/NIMH/RSA Child Advocacy Grants (1972).

A Review of Some Advocacy Efforts. It would be fruitless to cite and describe every effort which has the label of advocacy. Not all of these efforts are obtainable and can be described. Instead, the intent of this report is to condense and present seven advocacy efforts so as to depict their overlapping and unique features. The term "advocacy effort" is intentionally used because of the chaotic status of this field. It is our opinion that terms such as advocacy models or advocacy theories are currently not appropriate to use in assessing this field. Four of these efforts have some semblence of providing a conceptual framework, and they are: Advocacy for the Aged, Citizen Advocacy a la Wolfensberger, Ombudsman, and Advocate Counseling. The other three advocacy efforts represent concerned organizations or practices without conceptual frameworks or theories. These seven efforts are also analyzed according to advocate activities/roles and areas of advocacy impact, as exemplified in Table I. Given their literature, handouts and published materials, the project staff attempted to categorize these efforts in order to analyze any patterns. It should be noted that one effort, Citizen Advocacy, focuses mainly on personal advocacy, that is, solving client self-needs and the client's family/loved ones' needs. Other approaches, such as the Child Advocacy and the Association for Retarded Citizens, United Cerebral Palsy and Epilepsy Foundation, have a broader spectrum and focus on both personal advocacy and system advocacy. Two methods focus heavily on system advocacy, attempting to impact and change the local, state and federal institutions for the benefit of their clients. These are Lawyer Advocacy and Advocate Counseling. There are vast differences between these two approaches and these will be discussed later; however, for now, it is very apparent that the Lawyer Advocacy approach attempts to provide legal service on behalf of the client, whereas in Advocate Counseling, much responsibility for the actual solution of the problem is placed upon the client and his/her friends. The Ombudsman approach seems to focus on both personal and system advocacies, helping to solve problems concerning some client self-needs and family needs, as well as some institutional needs. Advocacy for the Aging also seems to encompass many strategies which impact upon both personal and system problems.

It is also important to note which approaches emphasize the performance of some advocacy service for the client, as opposed to the approaches which emphasize the teaching and learning of problem solving skills.

TABLE I

TYPICAL ADVOCACY EFFORTS

Potential Advocate Roles

Potential Areas of Advocacy Impact	Advocate "Does" for Individual	Advocate/ Individual "Do" Together	Advocate Teaches Individual
Client's Self Needs	AA, CA, O, ChA, ARC/UCP/EF	CA, ARC/UCP/EF	CA, ARC/UCP/EF
Client's Family/Loved Ones Needs	AA, CA, ChA, ARC/UCP/EF	CA, ARC/UCP/EF	CA, ARC/UCP/EF
Local Institutional Service	AA, CA, O, LA, ChA, ARC/UCP/EF	CA, ACM	CA, ACM
Local Institutional Policy	O, LA, ChA, ARC/UCP/EF	ACM	ACM
Local Institutional Ordinance	AA, LA, ChA ARC/UCP/EF	ACM	ACM
Local Institutional Litigation	AA, LA, ChA ARC/UCP/EF	---	---
State Institutional Service	AA, O, LA, ChA, ARC/UCP/EF	ACM	ACM
State Institutional Policy	AA, O, LA, ChA, ARC/UCP/EF	ACM	ACM

Legend

AA = Advocacy for Aging
CA = Citizen Advocacy
O = Ombudsman
ACM =Advocate Counseling Model
LA = Lawyer Advocacy
ChA =Child Advocacy
ARC =Assoc. for Retarded Citizens
UCP =United Cerebral Palsy
EF = Epilepsy Foundation

Continued next page.

TABLE I (Cont'd.)

Potential Advocate Roles

		Advocate "Does" for Individual	Advocate/Individual "Do" Together	Advocate Teaches Individual
Potential Areas of Advocacy Impact	State Institutional Legislation	LA, ChA, ARC/UCP/EF	ACM	ACM
	State Institutional Litigation	AA, LA, ChA ARC/UCP/EF	---	---
	Federal Institutional Service	AA, LA, ChA ARC/UCP/EF	ACM	ACM
	Federal Institutional Policy	AA, LA, ChA ARC/UCP/EF	ACM	ACM
	Federal Institutional Policy	AA, LA, ChA ARC/UCP/EF	ACM	ACM
	Federal Institutional Litigation	AA, LA, ChA ARC/UCP/EF	---	---

1. Advocacy for Aging. -- The major source of information for this effort comes from Advocacy in the Field of Aging (1975), a report by the U.S. Human Resources Corporation.

Advocacy "on behalf of" the elderly consists primarily of interest group politics, i.e., the interaction of one group with another to achieve a goal. It can be in the form of a group who represents the elderly or a group of elderly citizens representing themselves. Its goal is to link older people and services together.

These interest groups may seek to influence and/or pressure both government and business through the writing of letters, marches, protests, boycotts and speaches. Recently, the local, state and federal governments have had brought to their attention via group pressure the following problems: elderly citizens' dissatisfaction with cuts in welfare and medicaid, the desire for an increase in social security benefits, and the desire for lower income/sales taxes and transit fares.

Businesses have been approached to cut prices on food for the elderly. Banks have been asked to provide lower checking account and loan rates for the elderly.

Recently, professional people representing minority groups approached the White House Conference on Aging to make known the program needs for Black, Asian and Spanish speaking senior citizens.

Personal advocacy for the elderly deals mainly with everyday concerns such as 1) correcting or updating of resource files, 2) providing information about available services and agencies, 3) providing escort services, and 4) correcting agency errors in regard to specific cases.

In essence, advocacy for the elderly, in whatever form, is the working and pleading on behalf of older people for services that are at present non-existent or unavailable to them rather than those forms of advocacy services which help the older person to advocate for him/herself, hence become more independent.

The recently approved amendments to the Older Americans Act of 1965 (P.L. 94-135, November 28, 1975) provide a requirement that "Every State plan shall provide for the establishment or maintenance of programs (including related training) for the provision of some or all of the following services designed to assist older persons (i.e., 55 years of age and older) in leading independent lives and avoiding unnecessary institutionalization". The programs include " (3) Legal and other counseling services, and assistance programs, including tax counseling and assistance and financial counseling, for older persons."

2. Citizen Advocacy. -- The citizen advocate as outlined in W. Wolfensberger's Citizen Advocacy for the Handicapped, Impaired & Disadvantaged: An Overview (1972) is one who provides for both the "physical and emotional" needs of another. The citizen advocate is "...a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to be unmet without special intervention."

Wolfensberger identifies other forms of advocacy which are briefly:

1. Generic: advocacy for an entire category of persons -- (e.g., Ralph Nader)
2. Collective or Corporate: a group of individuals represent the interests of an entire category of persons -- (e.g., A.R.C.s)
3. Group Advocacy: usually informal group of citizens who serve as a "watch dog group" for another group -- (e.g., Church group who 'adopts' individuals in a nursing home.)
4. Multiple Advocacy: A citizen who advocates for more than one individual --
5. Dispersed Advocacy: Several advocates for one citizen --

6. Youth Advocacy: a youth serves as an advocate for another youth--

7. Advocate Associate: an individual who works within an agency and promotes change from within that agency --

These citizens when they become advocates should think of their commitment as long term associations. They adopt the strategy of "minimal advocacy" or that position which allows the person for whom they are advocating to do as much as possible on his/her own. The advocate, usually a volunteer, may be thought of as a friend who is there in need.

3. Ombudsman. -- The source of information for this "advocacy" effort comes from P. Linnane's Ombudsman for Nursing Homes: Structure & Process (1974). The ombudsman's role when contrasted to that of the advocate is similar in nature to that which is characterized as "Advocacy on Behalf Of". It is the role of the ombudsman to examine complaints and to act on those legitimate complaints in such a manner as to bring about a just conclusion to the citizen's problem by means of acquiring a service or securing a change in institutional policy. In the capacity of an advocate, it is not the role of the ombudsman to instruct. Although he is interacting with an individual in need, when the need no longer exists the relationship is terminated. It is his goal to provide for fair treatment to citizens and to give the citizen a sense of participation in the problem solving process.

The ombudsman, in his capacity as representative, does not have the power to make or reverse administrative actions. His power for change lies in his ability to criticize and publicize that which is unjust. Ideally, the ombudsman is characterized by impartiality, political independence and expertise in government which might place him in a unique position as a citizen representative.

Successful ombudsman activity calls for a substantial power base inside the system. Historically the ombudsman is appointed by a top official in government or an institution with responsibilities only to that person and authority to "cut red tape" on behalf of those who are confused by institutional or governmental policy and/or procedures.

The concept has been misused by some officials (notably in the business world) by calling their public relations persons ombudsmen. In other cases, the appointment of an ombudsman has been used to placate groups who have organized around a particular problem. In this case, the "ombudsman" serves as a buffer between the group(s) and the high officials.

Initially ombudsmen were elder statesmen respected, experienced and knowledgable in the workings of whatever context to which they were appointed. Of late, some programs have been initiated with persons of varying age and previous experience.

Research in the area of ombudsmanry is lacking and the traditional process by which an ombudsman works informal and unstructured. Hence, research data has been difficult to obtain.

4. Advocate Counseling. -- The information for this effort comes from two articles: a) "The Advocate Counseling Model: Part I - Conceptual Framework", 1974, by M. Brophy, A. Chan & B. Mar, and b) "The Advocate Counseling Model. Part II - The Process", 1974, by M. Brophy, A. Chan & R. Nagel.

The goal of the Advocate Counseling Model is to help people to assert maximum control over their own lives." The process described by this counseling model is focused on helping clients develop affirmatively assertive skills that will enable them to deal more effectively with dysfunctional institutional/individual interactions. Unlike other advocacy methods such as Child Advocacy, Lawyer Advocacy, Citizen Advocacy, etc., Advocate Counseling places primary emphasis on teaching and helping the clients to advocate for themselves so that they will ultimately be able to replicate, consistent with their capabilities and potential, the behaviors and methods utilized without the help of the Advocate Counselor.

This method is based upon the assumption that all human beings desire maximum capability for impacting upon those elements of the social order which effect their behavior. It posits institutions as a manifestation of a larger social contract. Institutions are perceived as entities created and sustained by agreements or contracts between individuals/groups of individuals/government for the purpose of serving some human need consistent with security for all. Further, as institutions survive the generations which created them the values represented by the agreements which brought them into being are imposed on succeeding generations. The role of the Advocate Counselor is to help individuals and groups maximize their impact upon the institutions in such a way that the institutions remain relevant in their efforts to meet the needs of those persons which they were established to serve. In this respect the process is geared to help institutions become stronger as they become relevant and responsive.

Institutions are perceived as the result of formal and informal agreements which culminate in the delivery of a service consistent with social order and security. Institutions must conform to standards of substantive and procedural due process consistent with the explicitly expressed concerns of the population served. Too often the security needs of those who are employed by the institution conflict with the changing needs of those whom the institution was established to serve. This is understandable, but ultimately socially destructive attitude on the part of some institutional employees often has a "chilling" effect on the due process by which the needs and grievances of individual clients and their friends are resolved.

This Model views the citizen/client as a hurting person who, in interaction with the institution, has not received adequate services and needs guidance a) to solve this immediate problem, short of litigation, b) to feel more in control of handling institutions, not destroying them, and c) to learn more about institutional behaviors as well as his/her own capabilities. The Model attempts a) to utilize the dysfunctional institutional problem as the client's own personal, living-learning laboratory, and b) to intensify/amplify the client's thought process and feelings in order to generate client assertiveness and action. This approach relies on the skillful application of accurate up-to-date, primary source information regarding institutions and their functioning, together with the elements of therapeutic counseling, such as empathy, warmth, respect, confrontation and assertive training.

Using the law as the highest authority, the Model teaches the client to look for discrepancies in the implementation of policies by institutional personnel and how to effectively utilize administrative procedures of due process. Much of this legal research education is done in an Information Resource Center, an action-oriented research facility containing primary and secondary source materials including statutes, relevant case law, rules &

regulations, administrative memoranda and operational rules of various institutions. Clients are taught how to utilize this facility, how to define the institutional problem, how to construct their own exhaustive list of alternatives and consequences, and how to implement the alternative of their choice. Because these are new behaviors for most people, the Model is also geared to handle conflicts and changes in thought processes, feelings, values and other personal-social insights.

The Advocate Counselor, as a helper, utilizes the skills of an educator, facilitator and implementor in aiding the client to obtain better and/or needed services from the institution. Such a helping person also maintains and makes accessible to the clients and their friends information from legislation, litigation and administrative memoranda. It is a primary function of the Advocate Counselor to insure that information disseminated to clients be as current as possible and that clients have an opportunity to ask questions and fully understand information. Whenever possible clients should also be given dated copies of relevant primary source information and/or specially prepared, dated memoranda on subjects relevant to their stated problem(s). This accurate information on which the credibility of the advocate counselor ultimately rests, easy accessibility of the service on a 24 hour basis, periodic follow-up and client referrals are the chief outreach mechanisms of the advocate counselor. With this method of advocacy, it is appropriate for either the advocate or the individual who has a problem to initiate a contact.

5. Lawyer Advocacy. -- Advocacy by lawyers is legal advocacy on behalf of an individual or class of individuals. In the area

of developmental disabilities, this is a relatively new concept. Black's Law Dictionary defines "lawyer" as "a person learned in the law: as an attorney, counsel, or solicitor; a person licensed to practice law." Also "any person who, for fee or reward, prosecuted or defends causes in courts of record or other judicial tribunals of the United States, or of any of the states, or whose business it is to give legal advice in relation to any cause or matter whatever. Act of July 13, 1966, article 9 (14 St. at Large, 121.)"

A lawyer represents another person or persons who has been injured by some action or inaction. A lawyer may perform a number of functions requiring some knowledge of the law. Many but not all of these functions have to do directly with litigation.

The literature reveals that these lawyer advocates are few in number in the area of Developmental Disabilities and as yet are not as well known as some of the other advocacy participants. Primary among the organizations utilizing advocacy by lawyers is The Mental Health Law Project.

The Lawyer Advocate may come in contact with a client on a "walk in" basis but as is usually the case the client is referred by someone else. The Lawyer Advocate may represent the client's individual needs where the problem is unique to the client or where a whole class of persons can be identified, a class action suit may be attempted.

The client referrals are usually via other advocacy programs, e.g., A.R.C. or professional agencies.

6. Child Advocacy. -- Major sources for this effort are many; however, several references will be cited here: a) Advocacy For Children (1972, 1974 issues), b) Various Developments in Child

Advocacy as Currently Practiced Throughout the U.S. by J. Reynolds (1975), c) Children Today, (1972 issue), d) Child Advocacy Systems: A Baseline Study (1971), e) A National Citizens Advocacy Model For Mentally Retarded Children (1972), and f) Child & Family Services of New Hampshire (1971-1974). Child advocacy is another system which represents "On Behalf Of" form of advocacy. Its goals are 1) to improve programs for children, 2) to assure that children or groups of children gain access to needed services, entitlements and help, and 3) to improve conditions which impede or may impede growth and development. Advocacy programs for children are many and diverse. They range from the National Center for Child Advocacy to state level organizations, such as the Kentucky Commission on Children & Youth to neighborhood organizations comprised of parents, youth and community church groups.

In Philadelphia, the Child Rights Center is an example of a neighborhood advocacy organization. It is their desire to expand and improve the service delivery systems which now exist. Their method is to develop the capabilities of neighborhood parents, youth and community residents in general. They desire to advocate for delivery of services and when necessary service or system change. Ultimately, they would like to develop a model for child advocacy which could be instituted in communities elsewhere.

The Child Rights Center's proposal is similar to the stated objectives of the Department of Health, Education and Welfare. In outlining what they feel to be necessary for adequate child advocacy, D.H.E.W. has focused on: 1) Improvement of institutional functioning, 2) utilization of neighborhood residents serving as advocates, 3) church group involvement, 4) advocacy as part of decision-making bodies of established organizations, 5) emphasis on institutional change in schools, clinics, recreational facilities and residential institutions, 6) emphasis on parent and citizen involvement, 7) the teaching of relevant laws to young people and parents, and 8) the establishment of state offices for children to provide an articulate focus for their needs. Organizations for child advocacy are seen to overlap in service. Children with handicaps are recipients of services from national organizations, e.g., United Cerebral Palsy Association, National Easter Seal Society and the National Association for Retarded Children.

Taken as a group, children would appear to have as much or more attention from advocacy efforts "On Behalf Of" than most groups.

7. Association for Retarded Citizens (A.R.C.), United Cerebral Palsy Association (U.C.P.A.) and Epilepsy Foundation of America (E.F.A.). Primary sources of information for these three organizations come from a) Implementation of Citizen Advocacy Through State & Local ARCs (1974), b) H.A. Benson's paper, "A Look to the Future" (1975), and c) H. Sands' paper, "Advocacy: A Method to Remove the Stigma From Epilepsy" (1974).

The A.R.C.s advocacy programs closely parallel the citizen advocacy model as outlined by Wolfensberger. The advocate is a volunteer who acts as a friend and advisor to the individual in need.

The A.R.C.s also engage in "corporate" advocacy where as a group the local A.R.C. represents the retarded citizen's rights on a given issue. On occassion, the services of a lawyer are required and secured. In the Milwaukee Chapter, there is an attempt to match the advocate and the protégé for similar interests and background. The new advocate receives training in the nature of advocacy, its expectations and the nature of mental retardation. The protégé's progress is monitored periodically and assessed for progress in specified areas.

The efforts advanced by the UCPA and EFA are mainly at the level of awareness building and issue generating. For example, Benson's paper addresses itself to the need for advocacy on behalf of cerebral palsied children and youth for preventative purposes. He is concerned with both personal and system advocacy. Sands' paper focuses on the need to remove the stigma from being epileptic and emphasizes the use of various advocacy procedures on behalf of these individuals. Not only should this stigma be removed from the epileptic individual but above all the stigma about these individuals must be removed from society. Advocacy via protective laws, monitoring and legal intervention are emphasized.

Advocacy by these groups has been supplemented on the national level by the activities of the Mental Health Law Project, an interdisciplinary public-interest organization devoted to protecting the legal rights of the mentally handicapped (and those so labeled). This group is sponsored by the American Civil Liberties Union Foundation, the American Orthopsychiatric Association and the Center for Law and Social Policy.

VI.

METHODOLOGY

A. Survey Construction, Content & Procedures

The project began on June 1, 1975, with a tentative itinerary/schedule as follows: During the months of June and July, questionnaires were constructed and pretested, and addresses of developmental disabilities boards and agencies were gathered. The survey began in August with local boards and agencies and a within-state regional survey. In September, it was expanded to a state-wide survey. The survey included an examination of the roles, relationships, structure, funding and current views of advocacy. October marked the starting point for an eight week examination of the information gathered to date which continued until the end of November, at which time the survey was completed. From the beginning of December, 1975, to the end of January, 1976, the project staff would write the final report which would include an advocacy model based upon the findings of the survey, a literature search and much staff discussions.

The final schedule (TABLE II) for surveying agencies, clients and local, regional, state and national units was as follows:

TABLE II

TIMELINE FOR ADVOCACY PROJECT

Date	Garland	Linnane	Brophy	Screven*	Chan
June wk 1 2 3 4	All to construct questionnaires, interviews, letter of transmittal, follow-up letter, pretest, etc.				Administrate, monitor enti project
July wk 1 2 3 4	Pretest Questionnaire				Help with survey development
Aug wk 1 2 3 4	Local, regional, state survey with direct service agencies and dev. disabled individuals	Survey adm. agencies & comm. bds.	Survey adm. agencies & comm. bds.		Coordinate staff travel
Sept wk 1 2 3 4			Analyze results		
Oct wk 1 2 3 4	Analyze results	Analyze results	Trip to Wash. D.C., examine nat'l programs		Analyze/ interpret survey
Nov wk 1 2 3 4	All to help compile progress report for Wisc. Co. on Dev. Disabilities by Nov. 21, 1975 all to be present at Council's meeting				
Dec wk 1 2 3 4	Literature review	Roles, interrelationships, diff. structures, costs, merits, etc.	Legal/ legislative implications	Evaluation component	Coordinate, edit writing
Jan wk 1 2 3 4	All to compile, write, etc. final report on multiple model of advocacy consistent with Objectives # 1 and # 2. Final Report in.				

*Rozanne Screven joined our project in late November, 1975, and was instrumental in developing the evaluation component and providing crucial feedback in different areas of the final report.

In pursuit of the most pertinent information available regarding the concept and practices of advocacy relating to the developmentally disabled, the research team chose to examine basically two groups: 1) developmentally disabled persons, and 2) various levels and types of agencies which serve the developmentally disabled. This latter group eventually became identified as: a) Administrative Agencies which included state level funding and supervisory agencies, planning agencies, as well as some federal funding and planning agencies, b) Community Boards (51.437), c) Direct Service Agencies (volunteer and professional agencies).

Questionnaires were chosen as the primary investigative tool. The development of the instruments demanded several attempts which began with one questionnaire for each group, i.e., one for the individual developmentally disabled person and one for the agencies which serve such a person.

The questionnaire for the developmentally disabled person was assigned the label "client questionnaire". (See Appendix: Developmentally Disabled Individual Questionnaire). The client questionnaire was designed in such a way as to consider the same questions pertaining to client services which would be found on the agency questionnaire. It was hoped that by doing this a measure of insight could be gained as to what rehabilitation facilities said they were achieving versus what clients felt they were actually achieving. For example, the sixteen service categories that were included in the agency questionnaire were also included in the client questionnaire, although different wording was used. Open-ended questions were asked in order to tap more directly those areas in which an advocate might serve a constructive role in a client's life. For example, one question asked for a description of the things an individual could do for himself and those things which required assistance.

The client questionnaire was field tested on individuals who were representative of the population to be sampled. That test led to numerous changes in the several drafts already designed. The final form consisted of thirteen questions. This final draft was designed as an interview form to be administered by a research office individual to preclude any bias on the part of either agency personnel or the client's family. The time schedule of the project called for the questionnaire to be administered to the client at the time of the research office's follow-up interviews with selected direct service agency personnel.

During the development of the questionnaire for agencies serving the developmentally disabled, it became apparent that one questionnaire could not account for the diversity of goals and responsibilities of the different agencies. Consequently, three questionnaires were designed reflecting more accurately the nature of the agency being examined and its relevance to the goals of the project. The three forms were: 1) The Direct Service Agency Questionnaire, 2) The Board Questionnaire, and 3) The Administrative Agency Questionnaire. These three questionnaires are presented in the Appendix.

The proposed Direct Service Agency Questionnaire was evaluated on several occasions by rehabilitation agency personnel whose input resulted in several alterations of both individual questions and general format. For example, it was found that the original draft was too lengthy and had to be shortened; requests for exact numbers were changed to estimations and approximate percentages; check lists replaced open ended questions wherever possible;

questions that would be of general interest, but not essential, were eliminated (e.g., "How much time elapsed between intake and the beginning of direct services?" or "Who made the initial contact with a prospective client?") and in general, there was a polishing of phrases and words (e.g., "non-professional" became "para-professional", etc.).

The Direct Service Agency Questionnaire was completed over a period of several weeks and in its final form consisted of three sections. Section 1 investigated the structure of the agency. Questions concerning the size of the agency, what services it provides and the like were included. Also investigated were the agencies' affiliations with others, what factors had proven to be most limiting, and what were sources of potential funding. Functions of agencies were looked at by asking about recipients of agency services and how client progress was monitored.

Section 2 was designed only for those agencies who had an advocacy component in service at the time the questionnaires were sent. These agencies were asked how their advocacy services were performed, what goals had been set, how advocates were selected and trained, and how clients were selected to be recipients of this service. Monetary questions were included, such as those regarding funding of advocacy programs.

Section 3 was for those agencies who did not have advocacy programs. This section asked many of the same questions as section 2 but in form of "how do you perceive" as opposed to "how do you achieve" or "do you know of" rather than "who".

The Board Questionnaire and the Administrative Agency Questionnaire were each divided into two basic parts. The first part of each questionnaire investigated the structure, budget, personnel, authority and purpose of the agency being examined. The second part explored the subject's views and experiences regarding advocacy. While the format of the advocacy section was essentially the same for both sets of questionnaires, the section on structure and function was distinctly different. In spite of, or perhaps because of, the specific nature of the questions in the first section, the diverse functions of administrative agencies contacted resulted in some questions being deemed inappropriate. For example, some respondents did not have the necessary data at their disposal. This was especially true of fiscal questions. The information asked for in other questions was considered confidential by the agency. In many cases, quantitative data was not made available to the interviewer out of concern for potentially unwarranted conclusions. A limited field test of both questionnaires occurred in late August with revisions leading to the reduction of a rather lengthy document. The final form was still quite formidable, but this difficulty could be traced to two factors: 1) the limited time for field testing, and 2) the relative dearth of information available regarding the nature of advocacy and its ramifications within the developmental disability arena.

Each of the four types of questionnaire was distributed throughout the state. In order to insure an adequate response which could produce meaningful data, it was decided to deliver several questionnaires in person and include an interview regarding the section on advocacy. The interview would follow a format identical to the questionnaire.

The decision concerning who would be interviewed was based on considerations regarding urban-rural differences, state-wide representation, designated poverty areas, multi-county boards, and percentage of services provided by a county versus percentage of contracted services. Finally, where time permitted telephone interviews supplemented the personal interviews.

B. Questionnaire Survey in Washington, D.C.

For a national perspective, one project staff member was sent to Washington, D.C. from October 16-23, 1975, for the purpose of a) examining other national groups working in the advocacy arena, b) locating potential sources of public funding of advocacy programs, and c) examining the latest developments in the Developmentally Disabled Assistance & Bill of Rights Act of 1975. The following names and their agencies/organizations were interviewed either personally or by phone:

1. Mr. Jackson M. Andrews (drafted advocacy portion of Developmental Diaabilities Act), minority counsel for the Senate Subcommittee on the Handicapped, Office of Senator Jacob Javitts (NY).
   Ms. Pat Forsythe, staff director for the Committee on the Handicapped.
   Ms. Ann Hocutt, professional staff member of this senate subcommittee, Office of Senator Jennings Randolph (W.Va.)
2. Mr. Al Rose, staff member for the newly formed Developmental Diaabilities Office in the Department of Health, Education and Welfare.
3. Dr. Leonard Perlman, Associate Executive Director of Government Liaison and Program Development of the National Office of the Epilepsy Foundation of America.
4. Mr. Harold A. Benson, Jr., Director of Government Activities Office for United Cerebral Palsy Associations, Inc.
5. Administration on Aging, Office of Child Development, Office of Community Services & Continuing Education, Bureau of Education for the Handicapped, the new Office of Consumer Education and the Office of Human Development.

In addition to the above period of contact, follow-up was maintained through January 15, 1976, with some of the above mentioned persons as well as contact with other persons and groups including the Mental Health Law Project and the Developmental Disabilities/Technical Assistance System. This information is included at the conclusion of the chapter entitled "Results and Interpretation" (See Results Analysis Update).

VII.

RESULTS AND INTERPRETATIONS

Survey In Washington, D.C.

For a national perspective, one project staff member was sent to Washington, D.C. from October 16th to October 23rd for the purpose of a) examining other national groups working in the advocacy arena, b) locating potential sources of public funding of advocacy programs, and c) examining the latest developments in the Developmentally Disabled Assistance & Bill of Rights Act of 1975.

During the time spent in Washington, D.C., approximately 16 persons (see Methodology chapter) were interviewed either personally or by phone. The interviews are organized in this paper according to the role of the persons interviewed in the development and formulation of the Developmentally Disabled Assistance and Bill of Rights Act of 1975.

I. Interviews with Mr. Jackson M. Andrews, Minority Counsel for the Senate Subcommittee On the Handicapped; Ms. Pat Forsythe, the Staff Director for the Committee on the Handicapped; and, Ms. Ann Hocutt, a professional staff member of the Senate Subcommittee On the Handicapped indicated that they all saw the Developmentally Disabled Assistance and Bill of Rights Act of 1975 as being strong and very significant for developmentally disabled citizens. The interviews focused on Title II of the Act entitles: "Establishment and Protection of the Rights of Persons with Developmental Disabilities." The subtitles of

Title II include "Rights of the Developmentally Disabled, Habilitation Plans, Protection and Advocacy of Individual Rights, Studies and Recommendations." It was indicated that the emphasis on rights for developmentally disabled persons would have significant implications for both procedural and substantive rights of due process and that this legislation would have a clarifying effect with regard to litigation subsequent to the passage of the Act. It was felt that with the evident commitment of the American Civil Liberties Union and the Mental Health Law Project in this area and the very specific language in the legislation that subsequent court decisions would be much more specific in such areas as "due process" and, as it relates to "least restrictive" environment, the definition of what constitutes "appropriate treatment". For example, questions such as "Do the dangerous mentally ill have a right to treatment when involuntarily confined?" and "Can the state confine the non-dangerous mentally ill against their will to give them treatment?" should be dealt with much more specifically in future court decisions as a result of this legislation.

It was indicated that the section on advocacy in the Act was left very broad with the intent that the states could determine what was meant by advocacy for themselves. It could be something like a consumers council or a Ralph Nader type of operation or any kind of operation that looks into, monitors and protects the rights of developmentally disabled citizens. It could be done in a university.

Senator Javitts of New York was particularly interested in the advocacy section of Title II. Senator Javitts' interest in this area has a long history and he was one of those primarily responsible for its inclusion in this Act.

All felt that it was important to monitor the agencies that are responsible for implementing the stipulations of the Act and subsequent litigation in such a way that those agencies, institutions and responsible person conformed to the intent and requirements of the law.

II. Conversation with a member of the staff of the newly formed Developmental Disabilities Office in the Department of Health, Education and Welfare:

This new bill is the first time for advocacy in the area of developmental disabilities. Previously the national council has discussed advocacy in the context of national significance programs. These are loosely called advocacy projects. In the past, they have been interested primarily in models utilizing professionals and community oriented programs. Areas of emphasis were technical assistance, utilizing computer based training and development of hospital standards.

The distinction between advocacy and protective services has been vague. Protective services has been interpreted very broadly. Any protection of the developmentally disabled citizen is a protective service. Advocacy may be subsumed under protective services. It is up to the local and state councils to develop the necessary distinction.

The regulations implementing the Act are likely to be more descriptive than definitive with the emphasis being on a very loose interpretation at the federal level of what constitutes advocacy. The optimum administrative location for an advocacy program might be in the private sector or it could be an agency of state government. It is possible that some funding will be done jointly with the Bureau of Education for the Handicapped and the National Institute for Mental Health.

III. Interview with Dr. Leonard Perlman, Associate Executive Director of Government Liaison and Program Development of the National Office of the Epilepsy Foundation of America:

Advocacy is used very broadly by the foundation. One must use affirmative means in advocating. Approximately one third of the estimated number of persons with epilepsy will not talk about their condition. They attempt to hide their disorder. They should come out front and admit that they have the condition. When this is done, it is possible to advocate for them in an affirmative manner.

An area of advocacy for the foundation is to educate physicians. Many physicians do not know how to treat epilepsy. Everything the foundation does fits into education. Advocacy is like education. Education depends upon having current information.

Another area of advocacy is the concern with standardizing the State laws regarding drivers licenses for persons with epilepsy. There are significant differences in the way States treat persons with epilepsy regarding obtaining a drivers license. The foundation is seeking information on legal rights of persons with epilepsy in various states. They have persons looking for the most equitable laws regarding people with a history of epilepsy. When these are compiled, the foundation will convene representatives from the various states in an effort to get the laws changed toward the end of some equitable standardization.

The foundation is also interested in consumer education advocacy. They are seeking to put people in the field who have a history of epilepsy and who would advocate on behalf of others who cannot advocate for themselves. They are also training vocational rehabilitation counselors, who, at the present time, generally have very few advocacy skills. The function of the persons in the field would be to act as liaisons between the local chapter and the local vocational rehabilitation office. Their purpose is to help people understand the vocational rehabilitation process and to help them handle any frustration in dealing with that process.

The distinction between advocacy and protective services is a question of semantics. Protective services comes under advocacy. If a person needs protective services, the advocacy role is stronger. Thst is, the advocacy role becomes stronger as the client does not have his/her needs met.

All groups are in need of advocacy services. It depends upon the individual as to what kinds of services he/she needs. Epileptics and those who are autistic are in great need of the services. They have been getting less than those who are mentally retarded, for example.

The optimum location for an advocacy program is at the state level until there is enough well trained advocates to function at the local level. To make the program most effective, it should be initially centralized and spread out from a strong center. The foundation's job is to reduce the need for having a foundation.

The advocate's job is to reduce the need for advocacy.

IV. Interview with Mr. Harold A. Benson, Jr., Director of the Government Activities Office for the United Cerebral Palsy Associations, Incorporated:

Mr. Benson, along with Ms. Beverly Rowan, an attorney with the Kennedy Foundation, worked with the conference committee in drafting the Title II of the Developmental Disabilities Act. A primary concern is how the regulations deal with habilitation, protective services and personal advocacy, and also how they establish standards for eligibility for services.

A primary concern about advocacy is that when most people hear the term, they associate it with confrontation. This is unfortunate. Those who are advocates should attempt to educate rather than confront. The achievement of deinstitutionalization should be a fundamental goal of any advocacy program. An advocacy program should concentrate on three elements: 1) Public Acceptance, 2) Public Awareness, and 3) Public Involvement. At the present time, not enough attention is being paid to the training of community personnel to cope with problems which will come with the deinstitutionalization of developmentally disabled persons. There are many programs that are retraining institutional personnel but for the future this is not as important as the training of local community personnel.

With regard to the distinction between protective services and advocacy, protective services are a part of advocacy. Qualified advocates need to be given more visibility. Many people tend to see advocacy only as a source of litigation rather than a source of institutional change without litigation. The latter is the primary goal of advocacy.

The term "least restrictive" is misleading. Rather, it should be stated in terms of being "most productive" in the sense that persons should be encouraged to develop their maximum potential. By comparison, "least restrictive" could mean, for example, the minimum amount of medication consistent with developmentally disabled persons' increasing their capabilities and having maximum opportunity for educational stimulation. "Most restrictive" might mean a person would be in restraints or heavily on drugs or living at home with no possibilities of increasing his/her capabilities and no educational stimulation. "Least restrictive" means availability of maximum opportunity to learn and do, develop physically and mentally.

The contract clause in the new Developmental Disabilities Act is particularly important. It has appeared in other legislation but the language was not quite as strong. This requirement to formulate a contract prior to treatment will force more emphasis on accountability, provided that it is monitored and there is a mechanism to encourage/enforce compliance.

A primary need is for the development of training programs to train trainers so that they can go out to local communities and train people in the community in responsible and effective methods of advocacy.

V. Other agencies in which persons were interviewed regarding advocacy included the Administration on Aging, the Office of Child Development, the Office of Community Service and Continuing Education, the Bureau of Education for the Handicapped, the new Office of Consumer Education and the Office of Human Development:

Previous advocacy programs and programs which might come under the rubric of advocacy funded by these agencies have not resulted in any kind of shared definition of advocacy. The tendency has been to consider advocacy primarily in relation to systems change and to associate the term with an adversary relationship. This has resulted in a popular assumption that advocacy leads to confrontation. The agencies contacted did not have their guidelines for proposals completed or approved at the time they were interviewed but it would appear that there are possibilities for joint funding in the area of advocacy with the Office of Human Development, the Bureau of Education for the Handicapped and possibly the Administration on Aging. The focus in these agencies, which have previously had advocacy programs, would seem to be on education with an understanding that the learning or development of programs emphasizing affirmative, assertive behavior may well fall within the purview of education.

State Survey Responsiveness

Following the mailing of the 63 direct service agency questionnaires (August, 1975), telephone contacts were made with approximately 29 of the agencies to whom questionnaires had been sent. The phone contacts were made in order to secure appointments with the agency directors. In discussing the answers given by the directors on the questionnaires which were completed in the presence of a research staff member, greater insight into those answers given on the questionnaires received by mail could be obtained. This interview also presented an opportunity for the initial contacts to be made with agency clients and an average of two interviews per agency were made in this manner.

By September 1st, 15 out of 63 possible agency questionnaires were returned to the research office. Beginning on September 2nd and continuing through the 4th, telephone contacts were made with those agencies that had not as yet returned the questionnaires. In all but a few cases (3) the agencies stated that they would complete the questionnaire and return it. In several cases another copy of the questionnaire was sent. One reason for the low return of the questionnaires during this time period may be because many agencies were undergoing funding renewal decisions and could not be bothered by our survey.

As a result of the low mail return from the direct service (voluntary and professional) agencies, project staff members decided to directly interview as many board and administrative agency personnel as possible during August and September of 1975.

The final returns of the questionnaire, phone calls and personal interviews for the developmentally disabled clients, the direct service (voluntary and professional) agencies, the administrative agencies and the community boards are presented in the following Figures 1 and 2 (included immediately after page 10 of this section).

The project staff personally interviewed 18 developmentally disabled individuals (from Milwaukee, Ozaukee, Racine and Dane counties) in relation to the appropriate questionnaire. Regarding the voluntary and professional direct service agencies, 43 responses were obtained out of 63 agencies throughout the state. Out of those 43 responses (which came from 24 counties), 25 were received via mail questionnaire and 18 interviews were conducted by phone. Follow-up personal interviews were done with 8 of these agencies for further elaboration. As for the community boards and administrative agencies, 35 responses were obtained (21 out of 56 community boards, 14 out of 26 administrative agencies). From these, 5 were received via mail, 2 by phone and 28 by personal interviews. In short, the project staff felt the survey was adequate, taking into consideration such dimensions as a) urban-small town-rural areas, b) varying developmental disability age groups, and c) varying disabilities. General feedback from those respondents indicated a lack of enthusiasm for the section on agency structure, function and linkages and mild interest to great enthusiasm for the section on advocacy. Project staff members expressed concern while developing these instruments that difficulty might be encountered due to the questionnaire's length. Feedback from many respondents confirmed our concern that this was an overambitious attempt to obtain too much information.

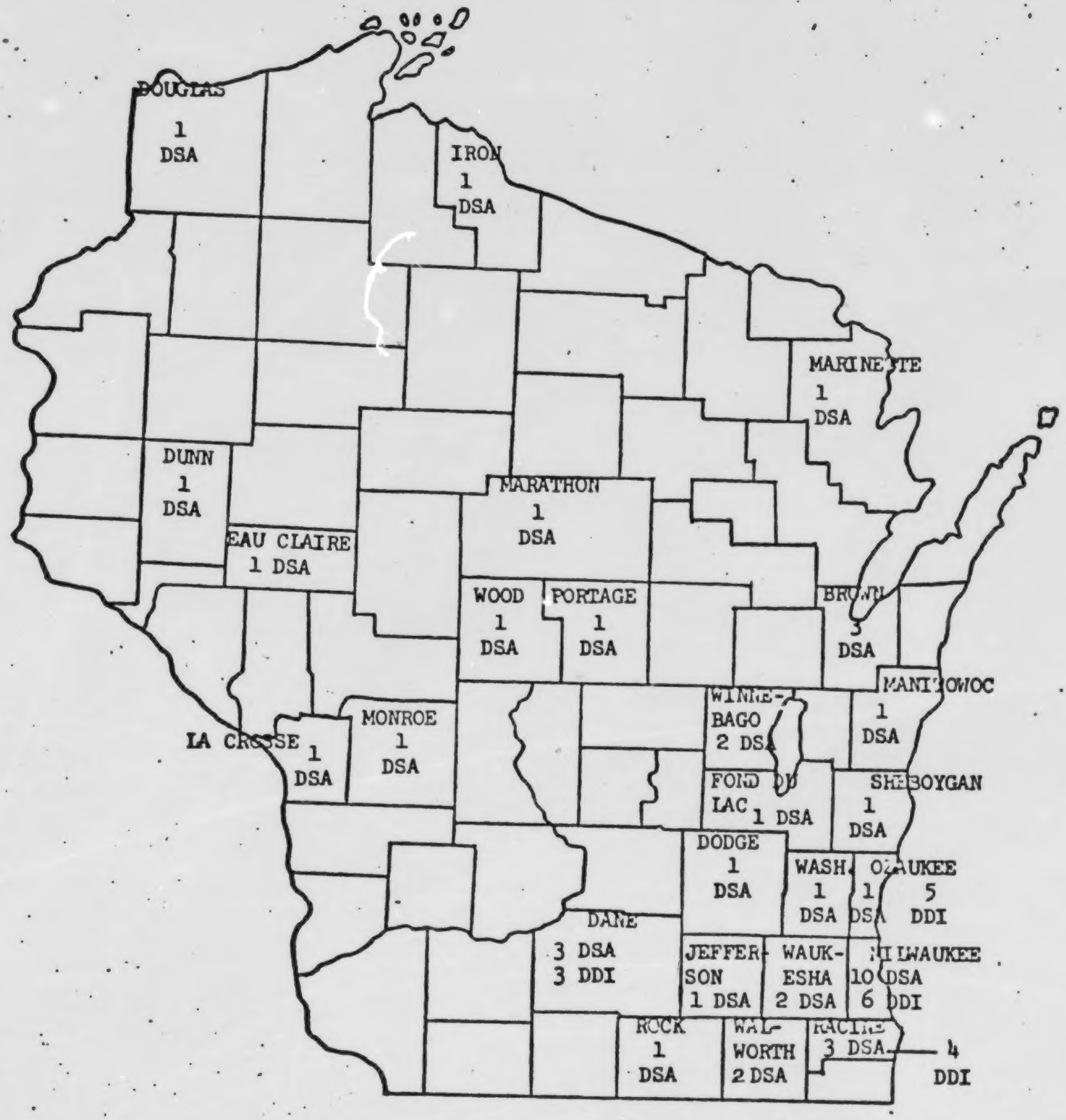
Findings from Survey Within State

Introduction: The total population surveyed has been divided into four main groups as follows:

1. Administrative Agencies, federal and state -- including those administrative agencies primarily responsible for making and interpreting policies regarding developmental disabilities;

FIGURE 1

SURVEY RESPONDENTS: DIRECT SERVICE AGENCIES & DEVELOPMENTALLY DISABLED INDIVIDUALS



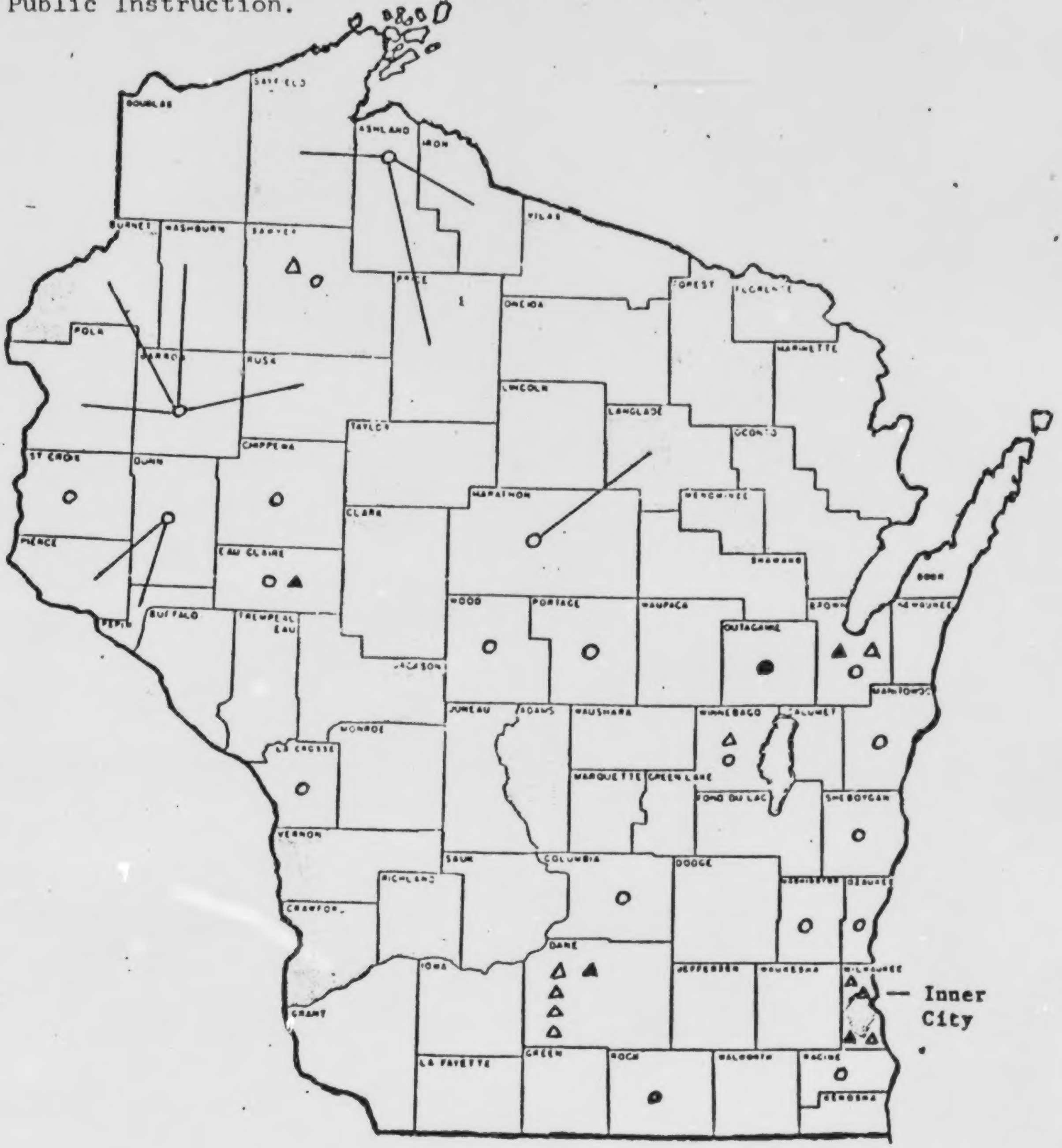
DSA = DIRECT SERVICE AGENCY (43 (25 mail, 18 phone, 8 personal interview))

DDI = DEVELOPMENTALLY DISABLED INDIVIDUAL (18)

FIGURE 2

SURVEY RESPONDENTS: COMMUNITY BOARDS & ADMINISTRATIVE AGENCIES

Questionnaires were sent to all 51.437 Boards in the state plus: (8) 'B' agencies; (5) DES regional offices; (5) DMH regional offices; Bureau of Mental Retardation; (2) Nursing Home Ombudsman (state & local); Governor's Committee on Children and Youth; Governor's Council for Consumer Affairs; Consumer Protection - Justice Dept.; Division of Health Policy and Planning; Health Policy Council; Dept. of Public Instruction.



○ Board Interview
△ Administrative Agency Interview
● Board Mailed Return or Phone
▲ A.A. Mailed Return or Phone

2. Local county boards in the state of Wisconsin responsible for implementing those policies;

3. Agencies responsible for providing direct service, consistent with those policies, to developmentally disabled citizens of the state of Wisconsin; and

4. Developmentally disabled citizens who receive those services.

The four questionnaires utilized in the survey have yielded substantial data regarding advocacy in general and especially advocacy for the developmentally disabled citizens of Wisconsin. Some key clusters of items on the questionnaires are particularly relevant to advocacy model building in Wisconsin: a) items on advocacy definition, goals and differences, b) disabled groups in need of advocacy and appropriate advocacy channels, c) ensuring "least possible restrictive" services, and d) items on administrative location of an advocacy program and possible funding sources.

There were wide discrepancies regarding the definition and goals of advocacy among administrative agencies, community boards and direct service agencies (voluntary and professional). In general, the community board respondents indicated a more specific knowledge of advocacy and its goals than did administrative or direct service agencies. The latter two levels had responses which varied greatly. It was evident from the results that advocacy means very different things to different individuals and agencies. This finding confirms assertions in the literature as well as our notion that chaos exists in the definition and scope of advocacy.

On all levels, respondents indicated that the mentally retarded are in the greatest need of advocacy services and that the

Association for Retarded Citizens (ARC), or some coalition of major agencies in the area of developmental disabilities, is the most appropriate channel for this help. This coincides with our impression that locally, state-wide and nationally, the mentally retarded individual is reportedly most in need of advocacy services and that channels for such efforts are relatively sophisticated. What about the cerebral palsy and epileptic individuals? Our findings reveal that these channels for advocacy are not as complex and sophisticated when compared to the ARC efforts. We find also that individuals with cerebral palsy, and especially those with epilepsy, are often ashamed to admit their disability and the attendant life problems incurred as a result of their affliction. The advocacy needs for autistic citizens are unknown. However, it is likely that the need for competent and responsible advocacy efforts for all of these citizens is great.

The inability of most agencies to determine and ensure that services provided for the developmentally disabled client are the "least possible restrictive," was indicated in our findings. This key "due process" concept must be defined and clarified if an effective state-wide model of advocacy is to be developed and implemented. For example, many respondents on the administrative, board and direct service levels saw grievances less as opportunities for clients, relatives, friends, etc. to participate in the process of service acquisition and delivery, than as an indication of failure and potential trouble.

The Results and Interpretation of the Developmental Disabilities Advocacy Survey.

I. Definition of Advocacy.

There is no definition of advocacy which emerges with anything close to a concensus from all the respondents. The major themes which prevail are: 1) doing something for the developmentally disabled citizen, and 2) helping developmentally disabled citizens to do something for themselves toward the end of maximizing their potential. Another theme which emerges is helping to protect the rights of developmentally disabled citizens. Virtually all respondents saw the function of advocacy as an ongoing process identified in part with everything they are doing. This questionnaire frequently represented the first time any of the respondents has ever attempted to organize his or her ideas about advocacy.

Examples of advocacy efforts, as described by the respondents, were as follows: Development of a consortium of agencies and organizations which work with the developmentally disabled in an effort to generate more influence to create more services.

--Adult girl comes to agency, bruised, dirty, with no previous diagnosis. She acts out and the medical personnel want her medicated. Parents do not want the developmentally disabled person medicated. An advocate might petition for removal from the home.

--Developmentally disabled person living in home conditions which are not conducive to development of any potential. The person is not able to do anything because he/she is controlled by members of the family. The advocate might work to improve the living conditions at home or if this was not possible might encourage the possibility of the developmentally disabled person moving or being moved to an environment which was less restrictive and more conducive to maximizing his/her potential.

--Developmentally disabled person wanted his/her guardianshop terminated. Advocate might work on behalf of this person. Such an advocacy effort might involve getting a determination from the court. It might also include a follow-up to determine whether the termination of the guardianship resulted in a subsequent situation for the developmentally disabled person which was better than that from which he/she came.

--A single developmentally disabled person with no strong family ties, not enough money to live independently and occasional problems with the law. An advocacy service might help this person to find services appropriate to their needs.

--Developmentally disabled person purchases an expensive item from a shop owner. This person has been solf this item and really has no evident need for it. An advocacy function might be to help this person manage his/her money better and/or possibly return the item and explain to the shop owner the situation in an effort to obtain a refund.

--Young woman living with parents who do not utilize the services of any community agencies. They are allowing her to sleep with whomever she wants. A brother sees this as potentially harmful for the girl and seeks to have himself appointed guardian. An advocate helps the brother to obtain guardianship and does subsequent follow-up.

--Other examples of advocacy include lobbying on behalf of more and better services for developmentally disabled; seeking better educational opportunities consistent with the changing legislation and litigation; making efforts to increase community awareness of the problems and potential of the developmentally disabled citizen; educating certified professionals such as doctors and lawyers with regard to the problems of developmentally disabled citizens and how they might better serve these persons in their professional capacity(ies).

II. Goals of Advocacy.

The various perceptions of the goals of advocacy tended to focus on safeguarding rights and providing needed services for developmentally disabled citizens. A smaller number of respondents emphasized helping the developmentally disabled citizen to function normally and develop their potential in a least restrictive environment. Other respondents indicated that advocacy effort should help acquire rights and responsibilities for developmentally disabled persons, as well as protect and sustain those rights and responsibilities already claimed and/or available through administrative action, legislation and litigation. Also, some indicated that a goal of advocacy should be to widen the public or societal awareness and acceptance of developmentally disabled persons as viable and productive elements of their everyday life. In relation to advocacy, there were no goals stated in such a way that could lead to quantitative analysis.

III. Differences Between Advocacy and Protective Services.

Among the respondents, there was general confusion with regard to the distinction between advocacy and protective services. There was a high degree of agreement that protective services are a structured and formal system with a narrow and legal base of activity. Protective services were generally seen in the context of formal or legal proceedings which culminate in action by a court of law. Advocacy was seen as more speculative, flexible and personal while being less formal. For example, the advocacy process would be one in which the developmentally disabled person might be encouraged to assume more responsibility and authority with regard to the decision making processes and actions related to the end result of the effort(s). An interesting distinction made by some respondents was that protective services might be seen more as a reaction, whereas advocacy might be seen more in relation to prevention or assertiveness. It was thought that an effective advocacy program might preclude the necessity for much of what is now understood as protective services. Some respondents indicated that advocacy is seen as an effort to help people do for themselves whenever possible, with whatever guidance/assistance is necessary; whereas protective services emphasizes doing something for someone, with or without their knowledge or acquiescence. Advocacy is seen as a learning experience that strives to allow an individual to live a life that is as normal as possible. This would seem to imply strongly that one goal of advocacy might be the continued replication of skills, including problem solving capabilities taught to the developmentally disabled client by the advocate. Other respondents perceived advocacy as part of a continuum of services which would lead to protective services; for example, a person with an effective advocate might not need protective services. The advocate would help the developmentally disabled person solve his/her own problem. Or if the advocacy service was not successful, it is unlikely that a knowledgable advocate would have minimized the potential for a positive result from the subsequent protective services effort.

IV. Service Categories In Which Advocacy Services Are Most Needed.

There tends to be general agreement that "special living arrangements" is that service category in which the largest number of respondents feel advocacy services are most needed. Many respondents indicated that protective socio-legal services are a category in which advocacy services are most needed. Most felt that this service was closely related to advocacy. Also, some felt that advocacy services in this category were particularly significant with regard to whether or not a developmentally disabled citizen was going to be able to function in the least restrictive environment in the community in which the special living arrangements were made. Some respondents also indicated that with the increasing impact on communities by the deinstitutionalization of the developmentally disabled, protective socio-legal and advocacy services would be a particularly significant factor in whether or not these efforts were successful. Although advocacy was not one of the sixteen service categories listed, some felt that this function should be one of the categories in which services are provided.

V. Developmentally Disabled Client Groups Most in Need of Advocacy Services.

The largest number of respondents felt that adult mentally retarded citizens were most in need of advocacy services. A significant number indicated that advocacy services were needed by those with multiple impairments. Virtually all respondents indicated that all of those client groups covered by the then current legislation for developmentally disabled citizens were in need of advocacy services. There was some feeling on the national level, as well as on the local level, that there are developmentally disabled client groups which are not covered by legislation but which are in need of advocacy services. These groups included elderly persons with organic brain damage and others who are severely disabled with other nervous disorders. Some respondents indicated that perhaps too much emphasis had been placed on the mentally retarded and that a greater focus should be placed on those who have cerebral palsy and are epileptic as well as, under the new federal legislation, those who are autistic. Considering age groups of developmentally disabled citizens who might most be in need of advocacy services, there was a concern felt by a large number of respondents that to place a priority on one age group might result in the bypassing of persons who were in need of advocacy services but did not fall into the age group category that was being given priority. The two age groups that were considered to be most in need of advocacy services were the 0-5 years of age group and 21 years of age and older.

VI. Optimum Administrative Location for Advocacy Programs.

Virtually all respondents agreed that any advocacy program for the developmentally disabled should be independent and free from pressures which might be brought to bear by special interest groups. There was also general agreement that such an agency should be highly visible and identifiable, and be able to reach and work with provider and professional organizations, as well as pertinent state and federal agencies. There was concern that those persons working in an effective advocacy program might be "cooled off" as a result of their efforts on behalf of developmentally disabled clients unless they had maximum freedom from outside pressures. It was frequently suggested that a non-profit corporation be created to house the program or that an existing organization with a history of working for the best interests of the developmentally disabled be granted the funds to supervise advocacy efforts. Concern was expressed that the funding source would support the advocate in independent activity; in particular, that activity which might impact upon federal, state or privately funded agencies related to providing services for developmentally disabled persons. Preferences for private community based organizations, locally funded, with a large amount of participation by client groups were often repeated. There was concern expressed that such an advocacy program should have ready access to all relevant information from agencies dealing with developmentally disabled persons. It was thought that many problems might be solved by just having easy access to current and accurate information relevant to developmental disabilities.

VII. Funding Sources for Advocacy Programs for the Developmentally Disabled.

A great deal of pessimism emerged from all respondents regarding possible funding sources for advocacy programs. Some interest was shown by national agencies concerned with the area of developmental disabilities. At this level, there is some interest in making an effort to combine funds from other federal agencies outside of the Department of Health, Education and Welfare with developmental disabilities funds in order to provide more services and facilities including advocacy. While local boards saw merit in advocacy proposals, competition among existing service deliverers and the need to create new services commands almost the total local budget. Administrative agencies queried were no more optimistic. Several program coordinators indicated that if matching funds were available, counties might be persuaded to commit some new funds to the area of advocacy. It was suggested that the WARC, United Fund, foundations and/or state or federal agencies might provide start-up monies for a well-planned advocacy program. Most respondents indicated wariness regarding any continued direct and total funding by the state or federal government for reasons stated above, unless there were safeguards adequate to insure the integrity of an advocacy program. Professional direct service agencies, which perceived of themselves as having a programmatic advocacy increment, expressed a need for further funding for this purpose. Also, professional direct service agencies stated that the time involved was a problem. At present, these agencies stated that funds to support an advocacy program would have to be appropriated from funds earmarked for other programs and that an advocacy program does not show a return for the money spent. Consequently, these agencies see such a program as a financial burden. Volunteer organizations have a somewhat different problem. They express a need for greater recruiting efforts, training programs and public education. Some funds will undoubtedly be available for advocacy programs via Title II of the Developmental Disabilities Act of 1975. However, it is likely that when the new regulations promulgating that act are published, the request for funds will be substantially less than the $3 million authorized by Congress for the first year. Organizations and agencies mentioned by respondents as possible funding sources for advocacy programs were as follows: Division of Mental Hygiene; Developmental Disabilities Office of the Department of Health, Education and Welfare; The United Fund; The National Association for Retarded Citizens; The Wisconsin Association for Retarded Citizens; The Ford Foundation; The United Cerebral Palsy Association; The Epilepsy Foundation.

Other groups, boards and agencies which respondents indicated might be cooperative or facilitative in initiating advocacy services were 51.42 and 51.437 boards, local ARCs and all county departments of social services. Some respondents from both the administrative agencies and the local boards saw the State Council on Developmental Disabilities as being potentially facilitative in the area of developing advocacy programs.

VIII. Problems to be Anticipated in Initiating and Maintaining an Advocacy Program(s).

Respondents indicated the following concerns regarding potential problem areas which might be encountered in initiating and maintaining an advocacy program:

Resource Allocation:-- There is keen competition between disability groups for available resources. It is possible that an advocacy program might utilize its resources to attack the distribution of services money by an allocating entity (e.g., a county board, a state agency, etc.). This activity could destroy the effectiveness of an advocacy program's effort if there were any question that the program was representing one disability group to the detriment of another. Also, resources are limited. An advocacy program should be required to maintain adequate proof that they are performing a positive service to both their developmentally disabled clients, friends, etc. and the agencies that also serve the developmentally disabled person.

Conflicts of Interest:-- An advocate employed in a federal, state or county agency, or even a private agency, may find him/herself subjected to substantial pressures intended to "cool them off" (coopt) via political and/or economic pressure. It is virtually inevitable that an advocacy process will contribute to the raising of untoward questions which some group, organization or agency might find untimely or even disruptive. Such efforts might conflict with the interests of the groups involved as well as the career interests of the person who is functioning as an advocate or advocate helper.

Lack of Knowledgable Persons:-- At the present time, there are few methods of advocacy which can be considered to be systematic models. Hence, there is a dearth of persons who have advocacy skills. Such skills might include those associated with an educator, a counseling therapist, legal research or at least some understanding of how the law operates, reading, writing, as well as individual, small group and large group communication skills. At the present time, there is no certification program for advocates and no training program which encompasses the increasingly large body of information regarding advocacy.

Type of Person:-- Age, sex, ethnic group and, with minimum qualification, physiological disability should prove no barrier to the type of person who might be trained as an advocate. Historically, those persons who have served in the role of advocate have been, like Cicero, persons with resources independent of the context in which they are advocating and/or persons with a passionate interest in a particular issue. At the present time, there is no career track for someone called an advocate. This does not mean that the skills involved are not transferable to spiritually and economically satisfying endeavors. Ideally, in selection of potential trainees, one might look for evidence of the patience of a saint, the temperament of a gad fly, the strength of a mountain climber, the grace of a tight-rope walker, the tact of a diplomat and it wouldn't hurt of he/she could leap over tall buildings and fly faster than a speeding bullet. Realistically, however, some of the qualities which one might look for in a type of person to be trained as an advocate would be a sense of the pragmatic coupled with a resolute commitment to change, faith that one can help the lives of others to be more fulfilling, tolerance of the weaknesses of others and recognition of their strengths, a high level of frustration and a belief in a system which can maximize the freedom and opportunity for others to develop their potential as well as a belief that where the system of which they are a part is not accomplishing its goal, it can be changed.

Insuring Program Integrity:-- Respondents indicated that integrity of the program and of program personnel which performed the function of advocacy is of utmost importance. Webster's New World Dictionary (1966, p. 759) defines integrity as "1. the quality or state of being complete. 2. the quality or state of being unimpaired. 3. the quality or state of being of sound moral principle." An advocacy program needs all three of these qualities. It should be complete in that as a programmatic entity it should not be required to conform to the goals of an agency or organization to which it might be attached. It should be unimpaired in that it should be responsible only to the objectives and goals established for its own programmatic success. And it should be of sound moral principle in that the emphasis on helping must focus on what the client or clients want rather than what the advocate wants.

Consistency and Ready Access to Accurate, Up-to-date Information:-- Virtually all respondents indicated that access to and ability to understand and disseminate accurate, up-to-date information is critical to establishing and continuing the credibility of any advocacy program. The acquisition, maintenance and discriminating dissemination of accurate information cannot be overemphasized as a necessary function of advocacy. This function of the advocacy process is a primary and essential outreach mechanism. Although other methods of reaching out to persons affected by developmental disabilities should be formulated and attempted, ultimately the most effective long term outreach mechanism for any human service agency is the lip-service credibility attributed to the service(s) provided by those served.

IX. Training.

All respondents indicated that if there was to be an advocacy program, training in various methods of advocacy is absolutely necessary. Respondents indicated that such a program should include a concentrated training period as well as an extended period of on-the-job supervision. Consistent with the above stated problems, the respondents suggested the following increments to such a program:

Communications Skills:-- Respondents indicated that it was important that potential advocates know how to listen and communicate with developmentally disabled persons and their friends and/or associates. Also indicated was a need to learn how to communicate with professionals who are already in the area of developmental disabilities as well as those who might be attracted to the possibility of contributing their skills. Those mentioned included professionals in law enforcement, business, medicine, dentistry and education as well as those already in the area.

Understanding the System:-- Many respondents indicated that there were already too many people telling service providers, boards and agencies how to do their job. It was felt that a thorough understanding of the means by which laws and policy are made, services provided for developmentally disabled persons is necessary. Concern was felt that persons who did not have an understanding of this system might antagonize persons within it so that the cure is worse than the illness.

Understanding the Developmentally Disabled Person:-- It was emphasized by many that persons who would function as advocates through the whole area of developmental disabilities should be exposed in a training program to persons with all forms of developmental disabilities. Some respondents indicated that this was particularly important if the advocate trainee had a great deal of experience with persons with one kind of developmental disability. They felt that this was important to mitigate any bias favoring persons with one kind of disability over those with multiple or other kinds of disabilities.

Evaluation:-- All respondents indicated the necessity of a comprehensive evaluation design and disciplined implementation within the context of a developmental disabilities advocacy program. Concerns mentioned included: a needs assessment involving those on the policy making level, those responsible for direct delivery of services, clients, as well as the advocate trainees; quantitative measures; qualitative measures.

Coordination with Other Advocacy Programs:-- It was also indicated that a training program should include an overview of other advocacy resources in such areas as consumer advocacy, nursing home ombudsmanry, lawyer advocacy, landlord/tenant advocacy, environmental advocacy and welfare advocacy among others.

Community Relations:-- Concern was expressed regarding the importance of mobilizing public support including the coordination of different groups, organizations and agencies working in the area of developmental disabilities. This concern with regard to training focused on the importance of recognizing the differences existent due to geographic area (e.g., urban-rural), local tradition and customs, as well as population density. There was concern expressed regarding the person who was not native to the geographic area performing the advocacy function in such a way that the possibility of misunderstanding and initial negative reaction might result.

Results and Interpretation Update (National)

This section of the final report is an effort to make the report as current as possible. Phone calls and personal interviews were conducted with some of the previous respondents as well as some persons which had not been previously contacted. These efforts continued through January 15, 1976.

It is likely that the regulations promulgating the Developmental Disabilities Act of 1975 will not be out until April 4, 1976. It is thought that the amount to be allocated for the remainder of the fiscal year 1976 (Ending for purposes of this Act on September 30, 1976) will be substantially less than the $3 million authorized by Congress. Figures mentioned were on the order of $1.5 million for fiscal 1976 with a reasonable possibility that the allocation for fiscal 1977 (Beginning for purposes of this Act on October 1, 1976, and ending on September 30, 1977) will be the full amount authorized (i.e., the figure $3 million).

It is also thought that the regulations governing the area of advocacy will be generally consistent with the language of the legislation which is: the "system to protect and advocate the rights of persons with developmental disabilities will have the authority to pursue legal, administrative, and other appropriate remedies to ensure the protection of rights of such persons who are receiving treatment, services, or habilitation within the state, and be independent of any state agency which provides treatment." It is also likely that the Department of Health, Education and Welfare will require the development and implementation of an evaluation design as an integral part of any advocacy program.

At the present time, oversight hearings (i.e., formal hearings help following the promulgation of the regulations refining a legislative act) are not planned regarding the Developmental Disabilities Act of 1975. Hence, it is important that interested persons seeking to refine this act consistent with their particular interests, react to these regulations as soon as possible (i.e., within 30 days) following the date in which they are published in the Federal Register. This thirty day period is one of the primary points in time in which an organization or person can have maximum inpact upon the regulations prior to the time they go into effect.

There are many concepts in law and professional practice which are relevant regarding advocacy for the developmentally disabled. Among those which have surfaced in interviews with respondents and promise to be of current and continuing relevance are the following:

"Right to Appropriate Treatment" -- Title II of the Developmental Disabilities Act of 1975 states "persons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities." The right to treatment is as yet not defined specifically. The holding in O'Connor v. Donaldson (45 L.Ed. 2d 396, June 26, 1975) stated "a finding of 'mental illness' alone cannot justify a State's locking a person up against his will, and keeping him indefinitely in simple custodial confinement," and later in the same decision it is stated, "in short, a state cannot constitutionally confine without more a nondangerous individual who is capable of surviving in freedom by himself or with the help of willing and responsible family members or friends." Mr. Bruce J. Ennis, an attorney for Donaldson, in an address before the annual conference of The Alcohol, Drug Abuse and Mental Health Associations on November 4, 1975, indicated that he believes that an additional finding of dangerousness must be coupled with a finding of mental illness to justify locking up a 'mentally ill' person against his/her will. Also he has indicated his belief that a state cannot constitutionally confine "without more 'than custodial care' a nondangerous person who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends."

The "Right to Treatment" for Persons with Developmental Disabilities has profound implications yet unknown for those making policy and directly serving the developmentally disabled. The process of refining this concept in law and in practice will be long and involved. The possible monitoring function of an advocacy program as well as the educational processes which will result from such a program should be of inestimable value to institutional personnel as well as hopefully mitigate the possibility or necessity for expensive litigation.

"Least Restrictive" -- The Developmental Disabilities Act of 1975 also states "the treatment, services, and habilitation for a person with developmental disabilities should be designed to maximize the developmental potential of the person and should be provided in the setting that is least restrictive of the person's personal liberty." This concept of "least restrictive" is another which has long term implications for policy makers and those responsible for direct service delivery to the developmentally disabled. It is likely that in the absence of substantial institutional initiative, courts will impose specific guidelines and stipulations on institutions refining this concept. A responsible advocacy program could aid institutions in taking positive initiative in this area.

Due Process -- the federal and state due process guarantees of the Fifth and Fourteenth Amendments to the Constitution have undergone a process of refinement as old as that document. It is only recently however that such guarantees have been applied to the developmentally disabled. One of the problems facing the mental health bar and other interested and active parties regarding the raft of new decisions in this area is the lag time between the date on which a decision from a court is handed down and its subsequent and continued implementation by relevant institutions. This problem was directly addressed by Mr. James W. Ellis, an attorney for the Mental Health Law Project, at a conference sponsored by the University of Maryland on Community Action Programs in the Mental Health Area in October of 1974 at which two of the authors of this final report were present. Trained advocates could help institutions and their clients to affirmatively assert themselves in a manner consistent with both the intent of the law and the charge of the institution.

Deinstitutionalization -- The process of deinstitutionalization of many developmentally disabled persons consistent with the Donaldson decision could be tragic unless the end result is truly a less restrictive environment for these people. Well trained advocates should prove of significant value in helping to implement such an outcome.

Conflict with the Law -- A review of current and pending state and federal ligislation, litigation and codes as well as discussions with attorneys and human service professionals reveals no conflict with the model for an advocacy program presented in this report. Rather this review and the discussions indicate that a responsible well structured advocacy program which helps people to more effectively participate in the continual process of adjusting the social contract to more fully meet their needs is an idea whose time has come.

Availability of Information -- The Government Information-Public Access Act of 1966, (P.L. 89-487, U.S. Congressional and Administrative News '66, p. 282,2418) has been the basis for slow but steady progress in making hitherto unavailable information regarding administrative policies available to interested parties. Coinciding with this act, a virtual explosion of publications digesting and compiling the Law and related information has taken place under the rubric of Law Reporters. Examples of recent Law Reporters which make readily available subject related information in a manner understandable to large numbers of people are the Family Law Reporter, Poverty Law Reporter and the Woman's Law Reporter. Although the authors of this report know of no current plans for such a service in the area of mental health or developmental disabilities, it would appear that with increasing numbers of people becoming interested in this area of administrative, legislative and judicial activity, the possibility of one of the major publishers in the area of law or even a public financed initiative could take place in the near future. In the absence of such an initiative, the accurate and up-to-date information required by a responsible advocacy program could be made available through a network of advocates in cooperation with public and private agencies.

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VIII.

IMPLICATIONS & RECOMMENDATIONS

Objective One deals with the development of definition and guidelines for the establishment of an advocacy program based upon information obtained from the following: 1) literature review of the problem area, 2) voluntary and professional state groups in cerebral palsy, epilepsy and mental retardation, 3) Task Committee on Health & Social Service, 4) Wisconsin's Nursing Home Ombudsman Program, 5) State Consumer Protection Agency, 6) Health Policy Council, and 7) national groups working in the area. Objective Two deals with the development of a model state-wide advocacy program which includes: 1) personal advocacy and system advocacy, 2) roles, interrelationships between various units in this endeavor, 3) merits and costs of different structures, and 4) evaluation of individual advocates, agency advocacy programs and the state-wide advocacy program. In order to answer these objectives and sub-objectives, this chapter is divided into the following topics:

A. Definition & Guidelines For Establishment of Advocacy Program
    1. Definition of advocacy
    2. Inclusion of system and personal advocacy within new definition
    3. Proposed multiple advocacy model.

B. Development of a Model State-Wide Advocacy Program for 1976 & 1977
    1. Recommendations for 1976 fiscal year
    2. Recommendations for 1977 fiscal year.

C. Other Important Considerations
    1. Roles/interrelationships between various organizations, agencies & boards
    2. Costs of advocacy
    3. Merits of public/private administrations
    4. Merits of local, regional or state organization
    5. Generic versus developmental disabilities specific.

A. Definition & Guidelines For Establishment of Advocacy Program

1. Definition of advocacy

Recent projects funded by various organizations have attempted to bring order out of the confusion surrounding the definition and scope of advocacy. Presently, the term "advocacy" is utilized so often to involve so many different activities that any person or group who helps another person or group is labelled an advocate. In short, any service or service-oriented program is often defined as advocacy.

From Wolfensberger's viewpoint, a citizen advocate is a "mature competent citizen volunteer representing, *as if they were his own*, the interests of another citizen" (Wolfensberger, 1972). According to Marie Moore, National Advocacy Coordinator for United Cerebral Palsy Association, Inc. (1974), advocacy systems for the developmentally disabled can be categorized into two general areas: 1) Case Advocacy which includes citizen advocacy, private and public ombudsman, legal advocacy and case manager advocacy, and 2) Class Advocacy which includes legislative advocacy, community organizational advocacy, program brokerage, protective service system and consumer action groups. In the recent study, *Advocacy in the Field of Aging*, done by the Human Resources Corporation (1975), the concept and activities surrounding advocacy were analyzed in terms of interest group politics. In this study, advocacy is defined as, "The exertion of influence, by a group in the arena of public policy for the purposes of eliciting change -- or causing the veto of proposed change -- for the benefit of a particular class or group of interests." It should be noted that in this last definition a conceptual framework is provided, that is, advocacy is seen predominantly as system or organizational advocacy, of an issue-oriented, public policy and political nature rather than individual advocacy which is more of a personal and episodic nature.

Our definition and scope of advocacy attempts to provide a conceptual framework from which to view the concept and its resultant activities. In addition, our definition takes into consideration the current statutory and constitutional aspects related to developmental disabilities. We begin with a value orientation about human interaction, that is, we believe that people support and help each other in times of need in the hope that eventually those helped will move towards some measure of independence and self-reliance· hence, a "least possible restrictive" environment for those helped. Without this value system shared by those in the advocacy arena, however defined, it would be useless to progress further.

Advocacy, therefore, is a word which describes an attempt to match/share the perceived greater resources of one individual/group or system with the dearth of those resources of another person/group or system with the end goal being to achieve maximal potential via participation, independence, productivity, affirmative assertiveness and responsibility in society. The resource may be knowledge, skills, wealth, goods, transportation, experience, intelligence. So may be the needs.

The term "use of resources" is intentional to include a variety of roles between those with greater resources and those with lesser resources. Specifically, the advocate (greater resources) may engage in two general roles with a developmentally disabled individual or group (those with lesser resources). From the perspective of the disabled individual/group, note that these two roles assume a continuum with dependence and minimal input by the disabled individual/group on one end to independence and maximal input on the other end. They are:

1. Advocacy On Behalf Of -- this means the advocate represents the interests of (advocates for) the developmentally disabled individual/group; the assumption is that the developmentally disabled individual/group is not currently capable of handling certain needs, problems and issues.
2. Self-Advocacy Instruction -- this means the advocate helps the developmentally disabled individual/group partially in handling needs, problems and issues, while attempting to teach the individual/group to identify the needs, problems and issues and move towards self-initiated solutions; the assumption is that the developmentally disabled individual/group is capable of learning and handling some problem identification and solution but needs varying degrees of support or help.

In short, we see advocacy as:

> AN INDIVIDUAL/GROUP OR SYSTEM WITH PERCEIVED GREATER RESOURCES WHICH REPRESENTS AND/OR INSTRUCTS SELF-INITIATED PROBLEM SOLVING EFFORTS OF ANOTHER INDIVIDUAL/GROUP OR SYSTEM WITH LESSER RESOURCES.

Advocacy in the above definition is a twofold process: 1) involving matching and sharing between greater to lesser resource units, and 2) involving an implementation process with a variety of representing and self-advocacy instructional roles. We see the above formula as providing a larger frame of reference from which to view advocacy, that is, there is a continuum whereby advocates perform services for or on behalf of developmentally disabled individuals to advocates performing some services while instructing individuals to problem solve for themselves. In addition, we see this definition as being consistent with a "setting that is least restrictive of the person's personal liberty", "maximizing the developmental potential" of developmentally disabled citizens (Developmentally Disabled Assistance and Bill of Rights Act of 1975). This definition furthermore is consistent with recent court cases involving right to treatment and due process, namely O'Connor v. Donaldson (45 L.Ed.2d 396) and Wyatt v. Stickney (344 F. Supp. 373 and 387, see also Wyatt v. Anderholt, 503 F. 2d 1305).

Many of the current activities of advocacy groups fall into the Advocacy On Behalf Of category, as opposed to the Self-Advocacy Instruction category. For example, legislative advocates and consumer advocates attempt to promote statutory and policy changes on behalf of the developmentally disabled as a group. In this sense, all administrative agencies, community boards and service providers are advocates. However, if we value the notion that all individuals, developmentally disabled or not, should have the right to move toward some measure of independence, self-reliance, assertiveness and responsibility, then there should be some way of determining how much representing or advocating on behalf of the developmentally disabled is necessary and essential. We feel that a specially created and designated advocate for the developmentally disabled should be one who identifies resource gaps which are not presently being met adequately or at all by the administrative agencies, community boards or service providers. The advocate on this redefined level initiates action by showing how or making a referral. He/she puts the burden on the individual or the family or the community. He/she does not perform advocacy. His/her ultimate goal is to put himself out of business. His/her immediate goal is to help the individual in such a way that he/she will be able to replicate the problem solving process with minimal or no help from the advocate in future situations.

Advocates for the developmentally disabled in the Self-Advocacy Instructional level will have the task of identifying the needs and problem areas of developmentally disabled individuals/groups and teaching them ways they can advocate for themselves.

2. The Inclusion of System Advocacy and Personal Advocacy Within This New Definition.

The concepts, "system advocacy" and "personal advocacy", are used in the literature by many groups usually to differentiate the impact level of advocacy. The former concept meant some individual or group advocate impacting upon a system in order to promote change for the developmentally disabled as a group. The latter concept meant some individual advocate impacting upon the developmentally disabled citizen or a system in order to promote change for the developmentally disabled person. Other names for the system advocacy are: organizational advocacy, class advocacy, interest group politics and issue-oriented advocacy. Differences between system and personal advocacies are noticable in terms of the initiator of the advocacy efforts, the recipient of advocacy effort (impact), the beneficiary of the advocacy efforts, and the problem identification-solution time line.

For system advocacy, the initiator may be an individual or group who starts the advocacy procedures, the recipient of the advocacy is usually some system or institution(s) who is not currently responding or is unaware of the needs of the developmentally disabled and the beneficiary is usually the developmentally disabled as a group. The time taken for such advocacy on the systems change level varies greatly. However, because changes are often sought in the statutory, rules and regulations and administrative memoranda levels, the time taken for such accomplishments is generally six months to several years. In addition, there is also the problem of *institutional lag*, whereby legislative changes take considerable time to filter through the various agency levels for implementation and appropriate service to the developmentally disabled individuals. Also such changes are often mitigated by problems of continuity of enforcement.

Individual or personal advocacy, on the other hand, distinguished itself by having one person as an advocate initiator and one person, the developmentally disabled citizen, as the beneficiary of the advocacy actions. Depending upon the particular need and problem, the recipient of advocacy efforts could be a) the developmentally disabled individual, if the need and problem involves directly and solely the individual, or b) an institution or system, if the need and problem involves the services by an institution to the developmentally disabled person. The problem identification and solution time line for personal advocacy efforts is generally short, relative to system advocacy efforts. It also follows logically that those in system advocacy choose problems and issues of a more universal nature affecting the developmentally disabled as a group, and those in personal advocacy choose problems of a more episodic nature affecting a single developmentally disabled person.

3. Proposed Multiple Advocacy Model

When we incorporate the system advocacy and personal advocacy concepts into our new definition of advocacy, the following multiple model emerges (TABLE III):

TABLE III

MULTIPLE ADVOCACY MODEL

Advocate Roles Along Dependence - Independence Continuum

Person(s) Needing & Benefiting From Advocacy	Advocacy On Behalf Of		Self-Advocacy Instruction	
	Personal	System	Personal	System
Dev. Dis. Individual	Citizen Legal Ombudsman	Legal Ombudsman	Citizen Case Mgr. Advoc. Co.	Case Mgr. Advoc. Co.
Dev. Dis. Group		Legislative Community organiz. Brokerage Protective Services Consumer	Advoc. Co.	Advoc. Co.

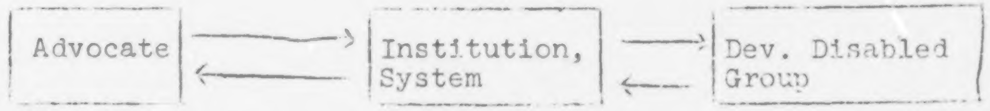
Almost all efforts can be conceived of within this multiple model. For example, many system advocacy efforts such as legislative advocacy, legal/lawyer advocacy, community organizational advocacy, program brokerage, protective services system and consumer action groups can be classified in the Advocacy On Behalf Of role, impacting upon a system for the developmentally disabled group. Citizen advocacy a la Wolfensberger appears to incorporate two roles, Advocacy On Behalf Of and Self-Advocacy Instruction, impacting upon either a system or the developmentally disabled individual for personal benefit. An ombudsman, as defined in Linnane's Ombudsman for Nursing Home: Structure & Process (1975) falls more into the Advocacy On Behalf Of role, although there may be some instructional rpocesses involved. Advocate Counseling, as developed by Brophy, Chan, Mar & Nagel (1974) focuses on teaching individuals or groups the skills of self-advocacy, impacting upon institutions for individual or group benefit toward the end of helping persons to affirmatively assert more control over their own lives.

Another way of viewing how current advocacy efforts within this multiple model is to focus on various schemata indicating the interactions between the principal actors involved, as in Figures 3 and 4.

FIGURE 3

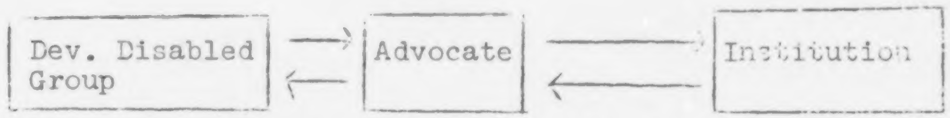
Schematic Depicting ADVOCACY ON BEHALF OF Roles

A.



Examples: legislative advocacy, community organization advocacy, protective service, consumer action, legal/lawyer advocacy.

B.

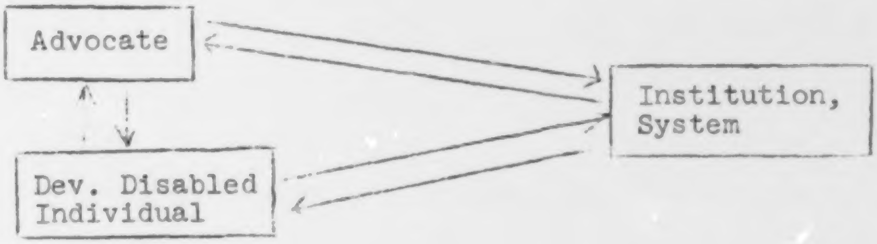


Examples: program broker advocacy, ombudsman.

FIGURE 4

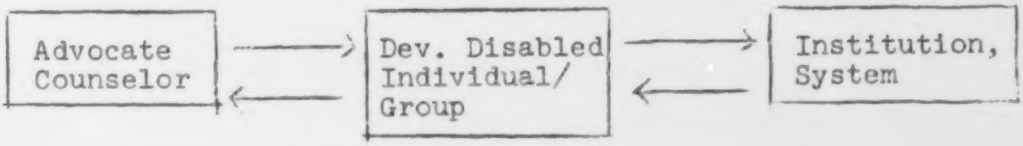
Schematic Depicting SELF-ADVOCACY INSTRUCTION Roles

A.



Example: Citizen Advocacy, case manager advocacy

B.



Example: Advocate Counseling

B. Development of a Model State-Wide Advocacy Program for FY 1976 and FY 1977.

The recently enacted Developmentally Disabled Assistance and Bill of Rights Act of 1975 (PL 94-103) mandates the following:

> "SEC. 113 (a). The Secretary shall require as a condition to a State receiving an allotment under part C for a fiscal year ending before October 1, 1977, that the State provide the Secretary satisfactory assurances that no later than such date (1) the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such system will (A) have the authority to pursue legal, administrative and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatement, services, or habilitation within the state, and (B) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities. The Secretary may not make an allotment under part C to a State for a fiscal year beginning after September 30, 1977, unless the State has in effect a system described in the preceding sentence."

Given the above statement, we proposed that the development and establishment of a state-wide advocacy program be divided into two phases according to the next two fiscal years (FY), 1976 and 1977. This proposed state-wide advocacy system attempts to incorporate the multiple advocacy model for FY 1976 and 1977 in order to meet the October 1977 legislative deadline. Emphasis during FY 1976 should be focused upon a) the development and implementation of training and evaluation procedures in multiple advocacy roles, and b) the coordination and establishment of a coalition of existing developmental disabilities advocacy efforts in order to manage/coordinate the state-wide advocacy system during FY 1977. Emphasis during FY 1977 should be focused upon a) further unification or coordination of existing developmental disabilities advocacy efforts, and b) the seeking of funds other than developmental disabilities monies.

The data thus far assembled and the staff discussions thus far held suggest that the Wisconsin Council on Developmental Disabilities consider the following factors when it chooses strategies for FY 1976 and 1977:

A. State-wide impact:- Whatever program decisions the Council makes, those decisions should reflect a concern for, as well as provide a mechanism to, impact upon every county in the state. The potential must be there for every part of the state to benefit from the program, taking into consideration such factors as urban-rural, poverty areas, minorities, and distribution of the developmentally disabled.

B. Definition and goals:- Careful attention should be paid to the definition of advocacy and the multiple advocacy model in order to project realistic and attainable goals and to provide a measure of program efficiency. Given the confusion and sometimes negative connotation surrounding advocacy, it is essential that the program project a clear and distinct image to the public of what it can and cannot do from the very beginning. Misunderstanding of the program's function based upon "vague goals, strong promises, and little impact," can cripple an effort of this nature.

C. Local initiative:- Interference from another state agency was a dominant theme for concern from many respondents. Therefore, the program should be so structured to encourage and support community participation in advocacy activity. As stated in P.L. 94-103, the program must be independent of any State agency which provides treatment, services, or habilitation to any persons with developmental disabilities.

D. Existing advocacy efforts:- The various advocacy efforts by the Association for Retarded Citizens, United Cerebral Palsy, and Epilepsy Foundation seem to operate independently of one another. The Council should consider steps which bring together a unified advocacy approach for all developmentally disabled citizens.

E. Multiple advocacy training:- Almost all advocates and advocacy programs lack the skills to operate on the various levels of personal and system advocacy. Some advocacy goals could be attained via less expensive efforts, less credentialed personnel. Training in multiple advocacy roles could be a great benefit to volunteers, agency personnel, boards members and administrative agency personnel.

F. Consumer input:- The participation of developmentally disabled individuals in this state-wide program is a must and can be considered at the local and state level. Consideration as to what manner of consumer input there will be should take both levels into account.

G. Technical assistance:- During FY 1976 and 1977 there will be questions about advocacy needs, training for volunteers, utilization of local resources, evaluation procedures, etc. which will require technical assistance.

H. Staff roles:- The question of whether the FY 1976 state-wide advocacy staff should be experts in developmental disabilities advocacy or both should be resolved before programming begins.

I. Program growth:- Consideration should be given to stabilizing the program beyond FY 1976. What controls, if any, should be placed on the amount of funding, size of staff, parameters of activities should all be decided before operation begins.

Keeping the aforementioned factors in mind, we would like to make the following recommendations for fiscal year 1976:

A. The state-wide advocacy system for FY 1976 should have the following functions:

1. to further identify advocacy training and evaluation needs of the developmentally disabled in Wisconsin;

2. to develop training materials in multiple advocacy roles;
3. to develop evaluation tools for assessing the efficacy of multiple advocacy roles undertaken;
4. to train those volunteers, agency personnel, board members, administrative agency members and developmentally disabled individuals interested in the implementation of multiple advocacy roles and their evaluation procedures;
5. to help bring about a unified advocacy coalition from the existing advocacy efforts for the developmentally disabled;
6. to stimulate advocacy efforts by local communities and particular interest groups;
7. to research apparent advocacy problems as well as new developments in the field of advocacy.

B. The staff for this FY 1976 endeavor would consist of:

1. one full-time administrator/coordinator;
2. two full-time staff/trainers of multiple advocacy roles;
3. one half-time field person to unify existing advocacy efforts;
4. one half-time volunteer coordinator;
5. one half-time research analyst/librarian/bibliographer;
6. one full-time evaluator (formative/summative roles)
7. one full-time secretary.

C. The Council would fund that project's activities for the most part, i.e., salaries, office supplies, telephone, traveling, rent, etc. However, counties, agencies and organizations would be required to participate in funding for particular programs in which they a) wish or b) are required by law to participate, such as training programs in the Advocacy On Behalf Of and Self-Advocacy Instruction categories as stated in the multiple advocacy model.

Since a state-wide advocacy system should be in existence by October 1, 1977, our staff discussions also led to another set of recommendations, for FY 1977, which took into consideration this deadline.

A. The state-wide advocacy system for FY 1977 should have the following functions:

1. to coordinate all developmental disabilities advocacy

efforts throughout the state and to coordinate any other advocacy efforts which might be related to a developmental disabilities need in some way;

2. to maintain unified advocacy efforts among those organizations who advocate for the mentally retarded, cerebral palsied, epileptics and other developmentally disabled individuals;
3. to coordinate the continued multiple advocacy training of volunteers, agency personnel and interested developmentally disabled individuals;
4. to develop a list of priority areas for which various advocacy efforts might implement;
5. to implement a variety of advocacy procedures and to assess their efficacy and impact;
6. to seek other sources of funding for the continued existence of such a project.

B. The staff for this FY 1977 endeavor would consist of:

1. one full-time administrator-coordinator;
2. one full-time field staff/trainer of multiple advocacy roles;
3. one half-time volunteer coordinator;
4. one full-time evaluator;
5. one full-time secretary.

C. The administrator/coordinator would represent the developmental disabilities advocacy office to the state, those organizations which deal with developmental disabilities, and county governments. The administrator would enter into agreements with counties, agencies, etc. which would hold the advocacy office to a commitment of effort in particular advocacy endeavors. This person would oversee the efforts of the advocacy office staff and would represent the office to the media. This administrator/coordinator would also continue to help maintain the unity among the various organizations utilizing advocacy approaches.

The recommendations for FY 1976 and 1977 account for statewide impact by making its resources available to the whole state and by collecting state-wide data. It defines its advocacy carefully to include support activities to would-be advocates and stimulation of advocacy efforts where they are lagging. It protects local initiative by not usurping the role of the community advocate. It would provide for consumer input and linkages with state agencies, service providers and technical expertise, through an advisory council which would make recommendations regarding direction and evaluation of program efforts. This proposed system, with its independent status from any particular interest groups within the arena of developmental disabilities, would also provide evaluation of local advocacy efforts and state-wide attempts at system change. Finally, it would offer control over growth with the goal being to move advocacy efforts to a level of self maintenance. The State-Wide Advocacy System would not become a large, rambling agency with a great percentage of its effort aimed at maintenance and growth of itself as a system.

C. Other Important Considerations

1. Roles/Interrelationships Among Various Organizations, Agencies & Boards.

Since our findings reveal that the volunteer organizations appear to have the time, resources and willingness to pursue advocacy as their central issue, the following is a recommendation concerning the possible relationship between volunteer direct service organizations, professional direct service agencies and community boards as they interact in their respective roles in the maintenance of a state-wide advocacy system.

The project staff feels that the responsibility for the initiation, maintenance, acquisition, selection and training & evaluation of advocates belongs to the volunteer organizations. These organizations would also have the responsibility of matching developmentally disabled individuals with advocates and the subsequent evaluation of the person's progress (in association with the professional direct service agency where appropriate). This unit would have the prerogative to accept or reject a developmentally disabled citizen for its services or to switch a citizen to a different advocate. The volunteer unit would have the prerogative to provide services for the disabled individuals who are not recommended or currently being served by a professional agency. It would also be the responsibility of the volunteer organization to insure the integrity of advocates and the advocacy agency plus disseminating information to the various professional agencies and the community-at-large to make their existence and services known. The project staff views the purpose of the 1976 state-wide advocacy program as identifying and aiding each volunteer direct service organization in achieving such efforts by October 1, 1977. Coordination and training in the various advocacy roles (Advocacy On Behalf Of and Self-Advocacy Instruction) should be a part of a state-wide advocacy program staff's efforts during 1976.

Following the previous idea further, the professional direct service agencies would first have the prerogative of review and approval of any and all working relationships with volunteer organizations in advocacy. Professional agencies could send those developmentally disabled individuals in need of advocacy to the volunteer (advocacy) organization for individual or system advocacy. The agency would play a role in the review of the individual's progress. It could also reject a given advocate if it felt there were sufficient grounds. The state-wide advocacy program for 1976 should identify and aid professional agencies in establishing such working relationships, towards the goal of meeting the October 1, 1977, deadline.

The Community (county) boards would review the proposed advocacy program of a volunteer organization and determine if it meets with established guidelines. If such is the case, then it is the board's responsibility to fund the program on the basis of program size, anticipated growth and need in a given area. The need would be based upon the number of programs already in existence and input from the professional agencies as to the need for that particular proposed program. It would also be the board's responsibility to ask for a periodic report from both the volunteer and professional direct service units concerning the maintenance of quality programs and to ensure that responsibilities are being met by each unit. The role of the FY 1976 state-wide advocacy program would be to meet with these local and county boards to help establish and encourage working relationships between the stated units.

2. Costs of Advocacy

There are basically two cost factors to consider. First, there are those obvious costs involving program payroll, outreach, housing and office supplies. These can be calculated and projected so that decisions can be made regarding size, location and level of operation of the program.

Second, there are hidden costs related to the success of some of the advocacy efforts, especially those geared to securing an increase of current services and the creation of new ones. These costs will appear in county budgets which must support the new and expanded programming.

Benefits will be much more difficult to measure. But whereever an advocacy effort has led to increased participation of a developmentally disabled person in society, there is likely to be a concomitant decrease in the need for societal supports which could be measured in dollar figures. A responsible advocacy effort should also eventually result in increased efficiency by institutions and agencies serving the developmentally disabled. Inefficient and ineffective individuals and programs might be more easily identified via the documentation which would result from an advocacy program.

Non-dollar costs and non-dollar benefits are worth exploring but only non-dollar benefits were suggested by the results of the survey. These include greater independence and life satisfaction for the disabled person, reduction of the emotional and psychological burden on the non-disabled person, and a growth in mutual understanding and appreciation by both the disabled and non-disabled.

Several service agencies also pointed out that an advocacy program would have to be paid for out of funds appropriated for other services thus jeopardizing their current funding levels.

3. Merits of Public/Private Administrations of Advocacy Program

The advantages, for the most part, appear to accrue to the private administration of advocacy programs. Private administration essentially provides a stance of independence and objectivity that is necessary in negotiations between county, state and federal regulators as well as the service providers. For the sake of this discussion, then, we see private administration as non-governmental and public administration as governmental.

A program situated outside government does not have to become entangled by established bureaucratic communication lines. It can take a stand without concern that it must treat all interest groups equally. It can mobilize more resources, such as the news media, to achieve its goals. It is less likely to become bogged down in the malaise generated by civil service hiring policies which keep some positions vacant unnecessarily long.

A problem of private administration would occur during the initial developmental stages of the program when effective linkages must be established between the advocacy office and government and service provider agencies. The temptation might be to establish the program under a state agency's aegis to facilitate its getting off the ground. Any gains so derived would be lost when the goals of the program differed from the goals of the agency and a conflict would arise which would adversely affect the credibility of the program.

Patience in developing full programming and the demonstration of competence in its early efforts will be enough to assure the program will be able to establish working relationships with whatever agencies or service providers it wishes.

Public administration may be attractive from another viewpoint, i.e., longevity. But since the goal of advocacy is not to establish itself as another layer of government and since the advocacy efforts may well be directed at changing government policy and procedure, it appears to be a contradiction to publicly administer advocacy programs.

Growth potential and occasional reduction of advocate activities also appear better suited to non-governmental administration. By growth, we do not mean in size and budget but in issues considered and variety of clients served. The program placed within a government structure would not have the authority to respond to needs which it recognized as worthy but were not currently listed by the government as appropriate subjects for the advocacy program.

It might be tempting during an initial program period to fund an advocacy program as a state agency with guarantees from the Governor and Attorney General of independence and access to relevant information and documents. This might be acceptable to the prime funding agent (DHEW). However, such guarantees are limited at least by the elective process and the continuity of such guarantees is always limited by the ability of each guarantor to exhaust their right to the processes available (i.e., negotiation, administrative due process, and possibly litigation) in resolving significant differences of interest and interpretation.

Such guarantees of ready access to information and independent action from the highest government officials can be given to a private agency as well as to a public agency. It is important that this guarantee effect private service agencies indirectly dependent on state funds as well as official state agencies. The credibility of an advocacy program is dependent on its ability to provide continuity of service, acquisition and dissemination of accurate and up-to-date information, and its ability to act independently when the interests of its client(s) conflict with the interests of other persons or institutions.

Although it is important that government take a positive interest in an advocacy program, it appears to us and, to a large degree, to our survey respondents that advocacy belongs as a citizen activity, not a government function.

A state office can provide linkages with the executive and legislative branches of government as well as existing lobbying interests. It can provide a reservoir of resources to regional and local offices. It can monitor state-wide advocacy efforts.

Living within the realities of limited budgeting, the best approach appears to be a state office which provides technical assistance to local communities or voluntary organizations in a how-to-do-it sense, thereby supporting and facilitating local advocacy endeavors. At the same time, the office might assume the leadership role in advocacy efforts of a state-wide nature, e.g., lobbying for legislative changes. A state-wide office does not assume that it must be located in the state capitol. Madison does offer immediate access to the legislature and state agencies. Other considerations, however, include the distribution of the developmentally disabled population and the access to technical assistance, which then favors Milwaukee.

5. Generic Versus Developmental Disabilities Specific

A generic program has as its most attractive feature a potentially wider funding base. Advocacy efforts need not be curtailed in any sense nor would efforts on behalf of the developmentally disabled in particular need to be severely restricted. In fact, contracts with the advocacy program could guarantee that advocacy needs would be met for any particular group. Efforts of the advocates would not become dissipated because the program responded to several different groups. On the contrary, the advocate program itself would have more to offer each group because of its diversified experiences in honing particular advocacy skills. The wider base for funding would also serve to insure a staff size sufficiently large to meet a variety of advocacy needs for a variety of clients.

Nevertheless, a developmental disabilities specific program, while operating under likely budget constrictions, would be able to provide not only advocacy support but also research and coordination resources. A specific program would not have to compete with other interests to establish a record and description of advocacy efforts throughout the state as well as join separate parties in common causes.

It is worth considering that an agency created and continued under the rubric of advocacy might be most effective if it remained one step removed from the actual process of advocating. The actual process of advocating tends to lead to a conclusion of bias and hence the possibility of a high and sometimes negative profile. This should be avoided as it will ultimately discourage some persons from seeking help who disagree with one position with which it is identified from utilizing the service in another situation in which it could be of help.

D. Evaluation

The primary role of evaluation is to provide information necessary to decision-making. Evaluation as a decision-making tool is typically used by higher level agencies and personnel, for unilateral decisions concerning agencies and personnel at lower levels. This "evaluation-from-above" frequently produces hostility and an uncooperative attitude toward evaluation. (Brophy, Maisto, Burstein & Chan, 1974). The evaluation model envisioned for a state-wide advocacy counseling program would provide for two types of decision-making:

1. decisions made by individual advocates or agencies concerning their own effectiveness;
2. decisions made by a higher level body regarding the effectiveness of lower level programs or individuals.

TABLE IV shows some of the decisions requiring evaluation input which might be made at each level of a state-wide advocacy program.

TABLE IV

A SAMPLE OF EVALUATION DECISIONS IN THE STATE-WIDE ADVOCACY PROGRAM

Advocacy Program Level	Decisions	Information Needed
State-wide Coordinating Body	Is the training program adequately preparing advocates for their needed roles?	No. of clients served; no. of problems eliminated/ameliorated; No. of clients raised from one level of independence to a higher level.
	Are all developmentally disabled populations in a given area being adequately served?	No. & types of disabilities served in each area; population of each disability in a given area; % of inquiries that were followed thru in each area.
	What is the degree of successful/unsuccessful advocacy outcomes?	No. & quality of systems impacted; problems identified for system & personal advocacy; action plans; quality & quantity of change reflected in statutes, rules & regs., admin. memoranda, operational rules, actual service.
Community Boards	Are volunteer advocacy organizations carrying out their programs adequately?	No. of clients served; average time taken for cases at each level of complexity; no. of each type of advocacy employed; No. of clients raised from one level of independence to a higher level.
	Is there a need for public awareness or agency impact programs not being brought to attention of local advocacy groups?	No. & type of inquiries received by boards or individuals other than local advocacy groups.

TABLE IV (Cont'd.)

Advocacy Program Level	Decisions	Information Needed
Community Boards (Cont'd.)	What is the degree of successful/unsuccessful advocacy outcomes?	No. & quality of systems impacted; problems identified for system & personal advocacy: action plans quality/quantity of change in statutes/rules & regs/adm. memos/oper. rules/actual service.
Local Advocacy Groups	Is there a need for more training by any volunteer advocate?	Ratings/scores on pre- & post-training: No. and levels of cases handled by each advocate; no. of clients raised to a higher level of independence, continuing degree of cooperation between agencies impacted and advocacy group.
	Is adequate information available in advocacy resource center?	No. of cases requiring delays due to inadequate information.
	What is the degree of successful/unsuccessful advocacy outcomes?	No./quality of systems impacted; problems identified for system and personal advocacy; action plans quality/qyantity of change in statutes/rules & regs/adm. memos/oper. rules/actual service.
	What priority areas emphasize immediate changes and opposed to long-term changes?	Quantity/quality of system problems considering institutional lag in policy implementation; identification & integration of critical decision-making centers by which to impact and change for immediate or long term results; quality of continuity of enforcement of changes which result from legislation/litigation.

TABLE IV (Cont'd.)

Advocacy Program Level	Decisions	Information Needed
Individual Advocate (volunteer or professional)	What is the client capable of doing for self? What type of advocacy approach should be employed and at what level?	Skills required for each level and type of advocacy: type of disability and limitations imposed by specific disabilities.
	What is the degree of successful/unsuccessful advocacy outcomes?	quality/quantity of persons/systems impacted; advocacy strategies chosen; quantity/quality of personal or system change.

The decisions cited in TABLE IV are merely a sample of possible decisions necessitating evaluation input. The responses to the questionnaire sent out through this project indicated that there is little agreement on, or even knowledge of, either the definition of advocacy, or the types of advocacy counseling needed by the developmentally disabled. Whether the ultimate state-wide advocacy program functions within the existing agencies and community boards, or is developed as an external system; there is still a need for cooperative action based upon agreement of needs and definition. Therefore, it would be beneficial to include some form of needs assessment in the first year planning and development stage of any advocacy program. This could be accomplished through a conference attended by representatives of the agencies and boards throughout the state; or by individual meetings between these representatives and the advocacy training program developers. Such a needs assessment would provide information pertaining to the goals and objectives of the training program, based upon community and agency input; and therefore, give these groups a share in the entire advocacy program.

A conference, chaired by developers of the training package, would have the advantage of providing a forum for ideas and lessen the threatening connotation that the term "needs assessment" tends to have.

Differences in needs and advocacy counseling approaches undoubtedly exist between rural and urban areas and between minority and major population groups. These differences can be defined and incorporated into the training program via a cooperative and organized needs assessment effort.

An important element in both the evaluation and the training aspects of the advocacy program, is the availability of self-evaluation instruments to enable both individual advocate and advocate groups to monitor or continuously evaluate their own effectiveness. This eliminates a considerable amount of the hostility mentioned at the beginning of this section which results from external evaluations for which criteria are unknown. It also provides feedback and information which enables advocates to improve their performance or to know what types of additional training or information are necessary to do so. This continuous self-evaluation instrument would have to be based upon objective, behavioral criteria for effective performance. In the case of individual advocates, these criteria would be defined by the objectives of the training program in relation to the decisions that must be made. For example, if one of the objectives of individual advocacy is to help a developmentally disabled client move from a condition of greater dependency to one of lesser dependency, then advocates would have to be provided with informatio which could help them define the entering and exit levels of the client's behavior and the amount of training or help to provide at each level of dependence. Figure is an example of one possible self-monitoring/decision-making instrument for individual advocates. It is a matrix of two variables. The variable on the horizontal axis shows the continuum of client resources from minimal social skills to the capability for doing legal research. The vertical axis indicates the complexity of the advocacy problem from individual volunteer advocacy to teach a client self-help skills to litigation at a federal level. There are, of course, other possible variables and decisions related to them. Figure 5 has been purposely left incomplete. Determination of the variables and decisions, based upon a needs assessment covering urban/rural and minority/major population characteristics, would be one of the tasks of the developers of the training program and/or the state-wide advocacy program coordinators.

This type of tool could provide help to individual advocates in their day-to-day decisions regarding the type of role they should take in their advocate-client relations and also provide them with criteria for determining whether they have moved a client from one level of dependence to a lesser level of dependence. The relationship between the client's level of dependence and the amount of advocate initiative is seen as being related to the "least restrictive-personal liberty" concept which has been left vaguely defined in the pending advocacy legislation. It behooves the advocate to allow the client to act for him/herself whenever possible and to foster optimum independence.

The type of matrix illustrated, if expanded and used as a recording instrument for all clients, could also provide information

FIGURE 5

POSSIBLE CONFIGURATION FOR AN ADVOCATE SELF-EVALUATION/DECISION-MAKING MATRIX

Potential Areas of Advocacy Impact

	Language ability, no ambulation or locomotion, dressing skills, eating skills, hygiene skills →	City transportation skills, job skills, leisure time skills →	Client Resources Reads, writes can articulate source of problem. →	Understands agency structure familiar with general legal implications. →	Capable of doing legal research
Self-help skill developmt. ↓					
Local institu. serv., policy, ordinance ↓	Advocate Behaviors and Resources Appropriate to give Client Resources/Potential Areas of Advocacy Impact.				
State institu. service, policy, legis., litigation ↓					
Federal institu. service, policy, legis., ligitation					

regarding the type of advocacy performed, problem/impact areas encountered or even strategies utilized. It also would function as a feedback instrument for the continuing adequacy of the training program. There are other formats for decision-making/self-monitoring evaluation instruments, but whatever type of instrument is created should have the following characteristics, to assure usage and maximal efficiency:

1. simplicity of design;
2. comprehensiveness of information provided and information obtained;
3. clarity of language.

Considering TABLE IV again, it becomes apparent that many of the decisions requiring evaluation information, at all levels of a state-wide advocacy program, could utilize the information obtained from a well-designed, comprehensive instrument without requiring reams of paperwork by individual advocates or agencies. For example, a decision by a community board concerning the effectiveness of volunteer programs could be partially answered from the self-monitoring/decision-making instruments by counting the number of individuals served, the number of different levels of advocacy employed and the number of clients who moved from a state of greater dependence to one of lesser dependence. A state-wide coordinating body could also determine the continued effectiveness of their training program utilizing the information from this type of instrument. Of course, the training program would have to be evaluated during development (formative evaluation) and after development (summative evaluation), but its continued effectiveness in the light of possibly changing advocacy needs by the developmentally disabled population could be continuously monitored through information obtained from a self-evaluation/decision-making instrument similar to the one discussed earlier.

An underlying assumption in the evaluation methods discussed here is the legal commitment to confidentiality of client records. All client records belong to the client and, therefore, require a signed release before information can be divulged, even for purposes of evaluation. Therefore, the major source of information for the periodic evaluations-from-above will, of necessity, come from information provided by individual advocates. The amount of bias in this information can be considerably reduced if the advocates know and understand the criteria upon which they will be judged and if they have an opportunity to improve their performances in relation to these criteria. This can be accomplished with a well-designed training program resulting in behaviorally stated self-evaluation/decision-making instruments. There are other methods for insuring the integrity of the information received from the advocates. One possible approach might be to provide a postcard complaint form to all clients during their first interview. The clients could send these forms to the state-wide coordinator or to the community board if they felt that the service they received was inadequate.

It is critical to the integrity of an advocacy agency that clients be fully informed, at the outset of the relationship, of the agency policy regarding confidentiality of verbal and written communications and documents. A more precise and comprehensive evaluation plan for the state-wide advocacy program would have to address itself to this issue of confidentiality in relation to information bias.

Thus, in summary, the final evaluation plan, as seen by these authors, would, ideally, consist of the following components:

1. a state-wide needs assessment to establish community related criteria, and agreement of definitions;
2. the incorporation of these criteria into the training program, along with training in the use of the self-evaluation/decision-making instruments;
3. utilization of a self-evaluation/decision-making instrument to make the individual advocates a more integral part of the evaluation process;
4. utilization of the same self-evaluation/ decision-making instrument for information regarding the continued effectiveness of the training program;
5. periodic evaluation-from-above based upon information provided by individual advocates and agencies, as well as spot checks of authorized client information, including voluntarily provided client information.

IX.

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X.

APPENDICES

A. Developmentally Disabled Individuals Questionnaire

B. Direct Service Agency Questionnaire

C. Administrative Agency Questionnaire

D. Community Board Questionnaire
(51.42/51.437 Boards)

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROJECT

CONDUCTED BY: SCHOOL OF EDUCATION, UNIVERSITY OF WISCONSIN-MILWAUKEE
DR. ADRIAN CHAN (PRINCIPAL INVESTIGATOR), PAT GARLAND,
MIKE BROPHY AND PAT LINNANE (414) 963-4798.

FUNDED BY WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES

WE ARE CURRENTLY CONDUCTING A PROJECT FOR THE WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES TO EXPLORE THE AREA OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED. WE ARE INTERESTED IN YOUR PERCEPTIONS OF THE PROBLEMS FACED AND THE SOLUTIONS OFFERED THE DEVELOPMENTALLY DISABLED.

AS WITH ALL INFORMATION WE GATHER, YOUR ANSWERS WILL BE CONFIDENTIAL AND CODED TO PROTECT THEIR SOURCE. THE INFORMATION GATHERED BY THIS SURVEY WILL BE USED FOR ESTIMATING THE NEED, FUNCTION, STRUCTURE AND AFFILIATIONS OF ADVOCACY PROGRAMS FOR THE DEVELOPMENTALLY DISABLED IN WISCONSIN

INDIVIDUAL QUESTIONNAIRE

NAME: ______________________________ DATE: ______________

AGE: __________

TYPE OF DEVELOPMENTAL DISABILITY:

_____ EPILEPSY

_____ MENTAL RETARDATION

_____ CEREBRAL PALSY

_____ MULTIPLE DISABILITY (PLEASE LIST)

____

____

____

____

PLACE OF RESIDENCE:

_____ HOME

_____ NURSING HOME

_____ OTHER: ______________________________
(PLEASE LIST)

DO YOU RECEIVE DAY CARE SERVICES: _____ YES _____ NO

AGENCY PRESENTLY PROVIDING SERVICES TO YOU. ______________________
(NAME OF AGENCY)

QUESTIONNAIRE ANSWERED BY:

_____ INDIVIDUAL

_____ FAMILY

_____ FRIEND

_____ GUARDIAN

_____ OTHER: ______________________________
(PLEASE INDICATE RELATIONSHIP TO INDIVIDUAL)

1. WHAT ACTIVITIES DO YOU LIKE? (PLEASE CHECK ( ) THOSE ACTIVITIES)

____ HOBBIES
____ GAMES
____ SPORTS
____ READING
____ MUSIC
____ TRAVEL
____ T.V. and/or RADIO
____ MOVIES
____ OTHERS: ________________________________
(PLEASE LIST)
____

2. DO YOU HAVE A CHANCE TO DO SOME OF THESE THINGS? ____ YES ____ NO

IF YES, HOW OFTEN?
____ MORE THAN ONCE A WEEK
____ ONCE A WEEK
____ ONCE EVERY TWO WEEKS
____ ONCE A MONTH
____ LESS THAN ONCE A MONTH

DO YOU DO SOME OF THESE THINGS WITH OTHERS? ____ YES ____ NO

IF YES, WITH WHOM?
____ FAMILY
____ FRIENDS
____ OTHERS: ________________________________
(PLEASE LIST)
____
____

3. WHAT DO YOU WANT THIS AGENCY TO DO MORE OF?

____
(PLEASE LIST)
____
____
____
____
____

4. WHAT DO YOU WANT THIS AGENCY TO DO LESS OF?

(PLEASE LIST)

5. WHAT DO YOU WANT THIS AGENCY TO DO FOR YOU PERSONALLY (OR FOR THE PERSON FOR WHOM YOU ARE RESPONSIBLE?)

(PLEASE LIST)

6. WHAT DO YOU WANT TO DO IN YOUR LIFE? WHAT ARE YOUR AMBITIONS (OR YOUR AMBITIONS FOR THE PERSON FOR WHOM YOU ARE RESPONSIBLE?)

(PLEASE LIST)

7. WHAT KINDS OF THINGS DO YOU DO BY YOURSELF?

____ A) GET UP/WASH/DRESS E) ____
(PLEASE FILL IN REST)
____ B) FIX SOMETHING TO EAT F) ____
____ C) GO SOMEPLACE OUTSIDE G) ____
____ D) BUY THINGS H) ____

8. WHAT KINDS OF THINGS CAN YOU DO BY YOURSELF WITH SOME HELP FROM OTHERS?

____ A) GET UP/WASH/DRESS E) ____________________
(PLEASE FILL IN REST)
____ B) FIX SOMETHING TO EAT F) ____________________
____ C) GO SOMEPLACE OUTSIDE G) ____________________
____ D) BUY THINGS H) ____________________

9. WHAT KINDS OF THINGS DO YOU HAVE OTHERS DO FOR YOU?

____ A) GET UP/WASH/DRESS E) ____________________
(PLEASE FILL IN REST)
____ B) FIX SOMETHING TO EAT F) ____________________
____ C) GO SOMEPLACE OUTSIDE G) ____________________
____ D) BUY THINGS H) ____________________

10. IF YOU HAVE OTHER PEOPLE HELP YOU, WHO ARE THEY?

____ FAMILY
____ FRIENDS
____ GUARDIAN
____ SOCIAL AGENCY: ____________________
(NAME OF AGENCY)
____ OTHER(S): ____________________
(PLEASE LIST)
____

11. ARE MOST OF YOUR PROBLEMS SOLVED THE WAY YOU WANT THEM TO BE SOLVED?

____ YES ____ NO IF NO, CAN YOU CITE ANY REASONS WHY NOT?

____
(PLEASE LIST)
____
____
____
____

12. WHAT PROBLEMS DO YOU HAVE WHEN YOU GO FOR HELP? (PLEASE CHECK ( ) THOSE PROBLEMS.)

SOMEONE MAKING A MISTAKE ABOUT:

____ A) WHAT TYPE OF DISABILITY YOU HAVE

____ B) WHAT YOU ARE ABLE TO DO (JOB, SCHOOL, ETC.)

____ C) TELLING YOU WHAT TO DO FOR YOUR PROBLEMS

I AM NOT HAPPY WITH

____ D) FOOD I RECEIVE

____ E) WHERE I LIVE

____ F) CLOTHING

____ G) EQUIPMENT (WHEELCHAIRS, ETC.)

____ H) TALKING AND DOING THINGS WITH OTHER PEOPLE

WHY? ____
(PLEASE LIST)

____

____

____ I) NOT BEING TAUGHT MY JOB

____ J) NOT BEING TAUGHT SKILLS LIKE READING, WRITING, ETC.

____ K) NOT BEING ABLE TO GET A FULL OR PART TIME JOB IN A REHABILITATION AGENCY.

____ L) COUNSELING

____ M) THE HELP I GET IN UNDERSTANDING THE LAW ABOUT WHAT RIGHTS I HAVE

____ N) TRANSPORTATION

____ O) OTHER PROBLEMS: ________________________________
(PLEASE LIST)

____

____

____

____

13. HAVE YOU EVER FOUND THAT WHEN YOU RECEIVED HELP FROM A SOCIAL SERVICE AGENCY THAT IT CAUSED YOU OTHER PROBLEMS?

____ YES ____ NO

IF YES PLEASE EXPLAIN ______________________________

____

____

____

____

____

____

____

NOTES: (PLEASE DO NOT WRITE BELOW THIS DOUBLE LINE!)

js
8-4-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY: School of Education, University of Wisconsin - Milwaukee
Dr. Adrian Chan (Pringiple Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.

FUNDED BY: Wisconsin Council on Developmental Disabilities.

____

____

We are currently conducting a project for the Wisconsin Council on Developmental Disabilities to explore the area of advocacy for the developmentally disabled. We are interested in your perceptions of advocacy, its need, its possible programmatic implementation and its problems. Specifically, we are asking individuals and voluntary groups and agencies, on all levels, their perspectives relating to this matter.

This questionnaire is divided into three sections. Please complete Section I. Then if you have an advocacy program, please complete Section II. If you do not have an advocacy program, ignore Section II and complete Section III.

All information gathered will be confidential and coded to protect the source (individual, group or agency) so that it cannot be used by others. The information gathered by this survey will be used for estimating the need, function, structure and linkages of advocacy programs for the developmentally disabled in Wisconsin. The questionnaire is not an evaluation of rehabilitation agencies. It is simply an instrument that will enable us to formulate an overview of services for the developmentally disabled in Wisconsin.

js
7-22-75

DATE: _____________

Person completing questionnaire: ______________________________

Position in agency: ______________________________

Name of Program or Agency: ______________________________

Location(s): ______________________________

What is your agency's geographic coverage?

City: _____ County: _____ State: _____

Number of years operating in present capacity?

Less than 1 yr: _____ 1 yr: _____ 2 yrs: _____ 2 yrs +: _____

STRUCTURE

1. Total No. of Staff: __________

	Full Time	Part Time
2. Number of Professional Staff:	_________	_________
Number of Para-professional Staff:	_________	_________
Number of Volunteers:	_________	_________

3. What type of groups do you serve? Please state numerically.

	Institutionalized	Non-Institutionalized
Developmentally Disabled (Mental Retardation, Cerebral Palsy, Epilepsy):	___________	___________
Emotionally Disturbed:	___________	___________
Multiply Handicapped:	___________	___________

4. Generally, how much of your agency's time and money are devoted to the following?

_____% - Direct care service time

_____% - Indirect care service time

_____% - Administrative time

_____% - Direct care service money

_____% - Indirect care service money

_____% - Administrative money

5. Please list the objectives of your program or please provide us with written material stating your agency's objectives (i.e., brochures, etc.)

____

____

____

____

6. How are you funded? _____% - Public; _____% - Private.

7. What services does your agency provide? In those service areas that you indicate, also indicate whether the population served is of heavy, moderate or light volume.

Diagnosis: *H__M__L__

Evaluation: H__M__L__

Treatment: H__M__L__

Personal Care: H__M__L__

Day Care: H__M__L__

Domiciliary Care: H__M__L__

Special living Arrangements: H__M__L__

Training: H__M__L__

Education: H__M__L__

Sheltered Employment: H__M__L__

Recreation: H__M__L__

Counseling: H__M__L__

Protective Sociolegal: H__M__L__

Informational & Referral: H__M__L__

Follow-Along: H__M__L__

Transportation: H__M__L__

*H=Heavy; M=Moderate; L=Light.

8. How does your agency determine what is the least restrictive and most appropriate service (in light of recent Supreme Court rulings) for the developmentally disabled client?

____

____

____

____

____

9. Briefly, what services does your agency contract for?

	Recipient of Contract
Psychological testing:	
Vocational testing:	
Sheltered employment:	
Other:	

10. Briefly, what services do other agencies contract for with you?

	Contracting Agency
Psychological testing:	
Vocational testing:	
Sheltered Employment:	
Other:	

AFFILIATIONS

1. Generally, what types of working agreements with government agencies have been basic to your operation?

2. Which government agencies have you found to be most helpful?

3. Do you (Director, Assistant Director) hold seats (voting or non-voting) on committees or boards of other agencies?

Yes: ____ No: ____

If Yes, please list:

a: ____ b: ____
c: ____ d: ____
e: ____ f: ____

4. What conditions do you see as having contributed most to the success of your program? Please list briefly:

a: ____ b: ____
c: ____ d: ____
e: ____ f: ____

5. Are there any factors which have limited the conditions of your programs? (Please check)

	Past	Present
Financial:		
Legal:		
Bureaucratic:		
Union:		
Staff (quality):		
Staff (quantity):		

(Question continued next page.)

5. (Continued from previous page.)

Others: a: ______________________________

b: ______________ c: ______________

d: ______________ e: ______________

f: ______________ g: ______________

FUNCTION

1. What is the total number of people you have served in the past calendar year? (Estimate if exact number is difficult to obtain.)

Grand Total: ________

2. What major factors affect the volume and nature of client contacts:

Financial: _____

Referrals: _____

Geographic Location: _____

Agency Size (Physical property): _____

Agency Size (Staff population): _____

Other: a: ______________________________

b: ______________ c: ______________

d: ______________ e: ______________

f: ______________ g: ______________

3. Do you employ any forms of outreach?

Yes: _____ No: _____

T.V.: _____

Press: _____

Brochures: _____

Speaking Engagements: _____

Other: ______________________________

____

____

____

4. How does your agency make its determination as to which individuals are in need of your services and which are not?

Referrals: _____

Testing: _____

Geographic proximity of
clients residence to agency: _____

Other: (please specify) a: ______________________________

b: ______________________ c: ______________________________

d: ______________________ e: ______________________________

5. Generally, what methods are employed to monitor the client's progress?

Within the agency: a: ______________________________

b: ______________________ c: ______________________________

d: ______________________ e: ______________________________

On the job placement: a: ______________________________

b: ______________________ c: ______________________________

d: ______________________ e: ______________________________

Other: a: ______________________________

b: ______________________ c: ______________________________

d: ______________________ e: ______________________________

SECTION II

FOR THOSE AGENCIES WITH ADVOCACY SERVICES

(If you do not have advocacy services, do not answer the questions in Section II. Move directly to Section III.)

1. Define advocacy as it is performed by your agency.

2. What do you see as the goals of advocacy services in your agency?

3. What do you see as the differences between advocacy and protective services? (As in Wisconsin Statutes, Chapter 284 (1973))

4. Approximately what percent of your entire agency program is devoted to advocacy efforts:

_____% of staff; _____% of budget; _____% of time.

5. How many persons do you have performing advocacy services: _______

Approximately, what is the turnover rate for your advocates within the last six (6) months?

0-10% _____; 11-20% _____; 21-30% _____; 31-40% _____;

41-50% _____; 51-60% _____; over 61% _____.

6. The average number of hours per week performed by these advocates is _____.

7. Advocacy services are provided for which of the sixteen (16) protective service categories?

Diagnosis: _____

Evaluation: _____

Treatment: _____

Personal Care: _____

Day Care: _____

Comiciliary Care: _____

Special Living Arrangements: _____

Training: _____

Education: _____

Follow-Along: _____

Sheltered Employment: _____

Recreation: _____

Counseling: _____

Protective Sociolegal: _____

Information Referral: _____

Transportation: _____

8. In addition to the above sixteen service categories, do your advocates perform other services, roles, tasks, etc.?

a: ______________________________ b: ______________________________

c: ______________________________ d: ______________________________

e: ______________________________ f: ______________________________

g: ______________________________ h: ______________________________

9. Those individuals performing advocacy roles are selected from inside/outside your agency. (circle one or both)

10. If your advocates are selected from outside of your agency, from what background and locality do you select them?

____

____

____

____

____

11. In addition, other characteristics of those performing advocate roles are generally:

_____% - males; _____% - females.

Estimated average age of advocates: _____ years.

Estimated average educational level: _____ years.

_____% - Volunteers.

_____% - Paid staff. Estimated average pay: __________

Estimated basis of pay scale:

Amount of time with agency: _____

Amount of time with advocacy: _____

Position within agency: _____

Educational level: _____

Other: ____

____

____

_____% - Blacks; _____% - Latins; _____% - Native Americans;

_____% - Asians; _____% - Whites.

12. If you have a training program for your advocates, please explain it briefly in terms of orientation, skills taught, length, supervision, etc.

13. How does your agency determine whether or not a client needs your advocacy services?

14. Please estimate the number and respective average ages of those clients served by your advocacy program.

	Number	Average age
Cerebral Palsy clients:		
Mentally Retarded clients:		
Epileptic clients"		
Multiply Impaired clients:		
Other clients:		

If others, please specify:

15. Are those needs which are expressed by the developmentally disabled client or his family the same as those found in the sixteen protective service categories? (See page 8.) If not, what specific client needs are unanswered and are amenable to advocacy roles?

16. What types of records are kept on the clients receiving advocacy services?

17. Please estimate loosely what percentage of the clients receiving your advocacy services are capable of the following? (Total = 100%)

a. _____% of developmentally disabled clients capable of solving their own problems without assistance.

b. _____% of developmentally disabled clients capable of solving their own problems with some guidance and instruction.

c. _____% of developmentally disabled clients capable of solving their own problems with maximal guidance and instruction.

d. _____% of developmentally disabled clients relying on advocates somewhat to solve problems for them.

e. _____% of developmentally disabled clients relying on advocates heavily to solve problems for them.

f. _____% of developmentally disabled clients relying on advocates completely to solve problems for them.

18. What types of feedback/evaluation efforts are undertaken on the advocacy services performed by your agency?

19. What kinds of problems are faced by your agency in providing advocacy services? (administrative, personnel, financial, etc.)

20. How are your present advocacy efforts funded? Please cite source.

21. Have you received information concerning outside agencies willing to fund advocacy efforts:

Yes _____; No _____

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? Please list.

____

____

____

22. What other agencies, groups or individuals do you know of, which also perform advocacy services for developmentally disabled clients in Wisconsin? Please list names, addresses, etc. if possible.

____

____

____

____

____

____

23. What groups, boards, agencies (local, regional, state) have been cooperative and facilitative in helping you achieve your advocacy service goals? How have they been cooperative/facilitative?

____

____

____

____

____

____

____

____

SECTION III

FOR THOSE AGENCIES WITHOUT ADVOCACY SERVICES

(If you have advocacy services, please respond to Section II and ignore Section III.)

1. Define advocacy as you perceive it and as your agency perceives it.

Uncertain: _____

2. What do you see as the goals of advocacy services with developmentally disabled clients?

Uncertain: _____

3. What do you see as the differences between advocacy and protective services?

Uncertain: _____

4. Which of the sixteen service categories do you think advocacy services are most needed in?

Diagnosis: ______

Evaluation: ______

Treatment: ______

Personal Care: ______

Day Care: ______

Domiciliary Care: ______

Special Living Arrangements: ______

Training: ______

Education: ______

Follow-Along: ______

Sheltered Employment: ______

Recreation: ______

Counseling: ______

Protective Sociolegal: ______

Information Referral: ______

Transportation: ______

5. In addition to the above sixteen service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

____

Uncertain: ______

6. Are the expressed needs of the developmentally disabled clients the same as the above sixteen service categories? If not, what specific client needs are unanswered and are amenable to advocacy roles?

____

____

____

____

____

Uncertain: ______

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services?

_____ Cerebral Palsy (specify age group: __________)

_____ Mentally retarded (specify age group: __________)

_____ Epileptics (specify age group: __________)

_____ Multiple impairment (specify age group: __________)

_____ Others (specify age group: __________)

_____ None of above group (reasons given: ____________________
____)

8. If you and your agency were to set up advocacy services, briefly describe how you might select and maintain individuals performing advocacy services. (Selection factors, preference for paid or volunteer program, etc.)

____

____

____

____

____

Uncertain: _____

9. If you and your agency were to set up an advocacy component, what might you include in your training/inservice program for individuals performing advocacy roles? (orientation, skills taught, length, supervision, etc.)

____

____

____

____

____

Uncertain: _____

10. How might your agency determine whether or not clients are in need of advocacy services?

____

____

____

____

Uncertain: _____

11. If you were to initiate advocacy services, please estimate loosely what percent of clients receiving these services are capable of doing the following: (total = 100%)

a. _____% of developmentally disabled clients capable of solving their own problems without assistance.

b. _____% of developmentally disabled clients capable of solving their own problems with some guidance and instruction.

c. _____% of developmentally disabled clients capable of solving their own problems with maximal guidance and instruction.

d. _____% of developmentally disabled clients relying on advocates somewhat to solve problems for them.

e. _____% of developmentally disabled clients relying on advocates heavily to solve problems for them.

f. _____% of developmentally disabled clients relying on advocates completely to solve problems for them.

12. What problems do you face if you were to set up such advocacy services in your agency? (administrative, personnel, financial, etc.)

____

____

____

____

____

Uncertain: _____

13. Have you received information concerning outside agencies willing to fund advocacy efforts?

Yes _____ ; No _____

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? Please list.

____

____

____

____

Uncertain: _____

14. What other agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in Wisconsin? Please list names, adresses, etc. if possible.

____

____

____

____

____

Uncertain: _____

15. What groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in setting up advocacy services in your agency? Please list and state how these might be cooperative/facilitative.

____

____

____

____

____

Uncertain: _____

js - 7-17-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY: School of Education, University of Wisconsin - Milwaukee
Dr. Adrian Chan (Principal Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.

FUNDED BY: Wisconsin Council on Developmental Disabilities.

We are currently conducting a project for the Wisconsin Council on Developmental Disabilities to explore the area of advocacy for the developmentally disabled. We are interested in your perceptions of advocacy, its need, its possible programmatic implementation and its problems. Specifically, we are asking individuals and voluntary groups and agencies, on all levels, their perspectives relating to this matter.

All information gathered will be confidential and coded to protect the source (individual, group or agency) so that it cannot be used by others. The information gathered by this survey will be used for estimating the need, function, structure and linkages of advocacy programs for the developmentally disabled in Wisconsin. The questionnaire is not an evaluation of rehabilitation agencies. It is simply an instrument that will enable us to formulate an overview of services for the developmentally disabled in Wisconsin.

Please return the questionnaire in the self-addressed envelope provided, after completion.

js
8-14-75

DEVELOPMENTAL DISABILITIES

ADMINISTRATIVE AGENCY* QUESTIONNAIRE

-I-

INTERNAL CONSTITUTION

(PLEASE PRINT OR TYPE ALL ANSWERS.)

1. Person(s) completing questionnaire:

name ______ title ______ phone ______

name ______ title ______ phone ______

2. Title of Agency: ______

---

* For the purposes of this questionnaire, the term "agency" includes division, council, bureau, etc.

INTERNAL CONSTITUTION

3. Please provide the following information regarding those employees of your agency who are assigned to work relating to 51.42/51.437 boards. (please print or type.)

Name	Job Title	Sex	Approximate Age	Racial-Ethnic Background*	Developmentally Disabled person?**	Number of years employed in this agency.	% of time assigned to work with 51.42 boards.	% of time assigned to work with 51.437 boards.	Phone

* Enter the proper number(s): 1. Black -- 2. White -- 3. American Indian -- 4. Latin -- 5. Asian-American -- 6. Other.

** Enter the proper letter: Y = Yes; N = No.

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-II-

BUDGET

1. What are the sources of your funds for developmental disabilities during this fiscal year, i.e., 7/1/75 - 6/30/76? (Indicate name of source and amount and/or percent of total.)

$ and/or %
source
$ and/or %
source
$ and/or %
source
$ and/or %
source

2. To whom does your agency allocate funds? (Indicate name of agency and percentage of total allocated and/or amount for each agency. If space provided is not adequate, please attach a list.)

$ and/or %
source
$ and/or %
source
$ and/or %
source
$ and/or %
source

3. What legislative and administrative sources outside of your agency have been most helpful to you when questions relating to fiscal policy arise? (Please check all that apply and circle those which have been most helpful.)

___ U.S. Code
___ Code of Federal Regulations
___ Wisconsin Statutes
___ Wisconsin Administrative Code
___ The State Plan for the Developmental Disabilities Act.
___ County Corporation Counsel
___ Area-wide Comprehensive Health Planning Agency ("B" Board)
___ Division of Health Policy and Planning
___ 51.42 Board
___ 51.437 Board
___ Developmental Disabilities Board
___ Department of Public Instruction

(Cont'd. next page)

3. Cont'd. from page 3.

__ Division of Mental Health

__ Division of Vocational Rehabilitation

__ Division of Family Services

__ Other: ______________________________
please indicate

____

4. What percentage and/or amount of your funds for fiscal '74 (i.e., 7/1/74 - 6/30/75) and fiscal '75 (i.e., 7/1/75 - 6/30/76) were designated for each of the service areas listed below:

Service Areas	Past Fiscal Year		Present Fiscal Year	
	% and/or	$	% and/or	$
1. Evaluation:				
2. Diagnosis:				
3. Treatment:				
4. Day Care:				
5. Training:				
6. Education:				
7. Sheltered Employment:				
8. Personal Care:				
9. Domiciliary Care:				
10. Special Living Arrangements:				
11. Information and Referral:				
12. Counseling:				
13. Follow-along:				
14. Protective:				
15. Recreation:				
16. Transportation:				

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-III-

CONTACT WITH OTHER AGENCIES

1. List the administrative agencies and boards with whom you have formal contact regarding developmental disabilities. (List agencies and number designating kind(s) of relationship(s).*)

Agencies	Relationship*
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other
______________________	/ / / / ____________ other

* Enter the proper numbers and/or explanation under Relationship as follows: 1. Funding -- 2. Evaluation -- 3. Consultation -- 4. Planning -- 5. Other.

2. What agencies with responsibilities in the area of developmental disabilities do you regulate? (check all that apply -- Please attach a list if the space provided after "other" is not adequate.)

___ All the agencies which you fund.

___ Other: ____

____

____

2.1 How often do you evaluate these agencies? (check all that apply

___ Monthly ___ Semi-annually

___ Quarterly ___ Annually

___ Other: ____
please specify

2.2 What do you do with the results of the evaluation?

____

____

____

3. How and by whom is your agency evaluated?

____

____

____

4. How often are you evaluated? (check all that apply.)

__ Monthly

__ Quarterly

__ Semi-annually

__ Annually

__ Other: ______________________________________
please explain

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-IV-

ADVOCACY

1. Define advocacy as you perceive it.

____

____

____

Uncertain: ____

2. If your agency has ever expressed its perception of advocacy, please describe it.

____

____

____

3. What do you see as the goals of advocacy services with developmentally disabled clients?

____

____

____

Uncertain: ____

4. What do you see as the differences between advocacy and protective services?

____

____

____

Uncertain: ____

5. In which of the sixteen service categories do you think advocacy services are most needed? (check all that apply -- circle "most needed" category.)

Diagnosis: _____

Evaluation: _____

Treatment: _____

Personal Care: _____

Day Care: _____

Domiciliary Care: _____

Special Living Arrangements: _____

Training: _____

Education: _____

Follow-along: _____

Sheltered Employment: _____

Recreation: _____

Counseling: _____

Protective Sociolegal: _____

Information Referral: _____

Transportation: _____

6. In addition to the above sixteen service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

Uncertain: _____

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services? (check all that apply -- circle group most in need.)

__ Cerebral Palsy (specify age group: __________)

__ Mentally retarded (specify age group: __________)

__ Epileptics (specify age group: __________)

__ Multiple impairment (specify age group: __________)

__ Others (specify age groups: __________)

__ None of the above groups (reasons given: ____________________
____)

8. Briefly, describe what you believe to be the optimum administrative location and funding source for advocacy programs.

____

____

____

Uncertain: _____

9. Have you received information concerning outside agencies willing to fund advocacy efforts? (check one.)

__ Yes __ No.

If Yes: Please list those with which you are familiar:

____

____

____

10. What agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in your geographical area of jurisdiction? (Please list names, addresses, etc. if possible. Attach list if space provided is not adequate.)

a. ______________________________

b. ______________________________

c. ______________________________

d. ______________________________

e. ______________________________

11. What other groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in initiating advocacy services? (please list ans state how these might be cooperative/facilitative.)

____

____

____

Uncertain: _____

12. Do you currently regulate/fund any advocacy programs?

__ Yes __ No.

If Yes, answer questions 15 through 19.

If No, answer questions 13 through 19.

13. If your agency was to initiate advocacy services, briefly describe what you believe to be the optimum administrative location and funding source for such programs under your jurisdiction.

14. What problems do you face if you were to initiate such advocacy services? (administrative, personnel, financial, etc.

15. What is the source of funds for your advocacy program(s)?

16. How does your agency ensure that services to developmentally disabled citizens served by agencies are the "least possible restrictive" on their personal liberties?

17. How often did developmentally disabled clients or their representatives present your agency with a grievance during the past twelve months? (check one and indicate number.)

__ Exactly: _____

__ Approximately: _____

18. What are the most common types of developmentally disabled client grievances that come to your agency?

a. ______________________________

b. ______________________________

c. ______________________________

19. If your agency is unable to resolve a grievance from developmentally disabled client or their representative, what do you do?

____

____

____

APPENDIX I

DOCUMENTS

1. Please enclose a copy of your by-laws and operating procedures with this completed questionnaire. If this is not available, please describe your responsibility and authority below:

2. If you have documents regarding funding criteria, priority areas, standards for acceptance or rejection of requests for funds, etc., please enclose them with this questionnaire. If not, please describe such criteria below:

3. If you are required to conform to a formal reporting mechanism, please enclose a copy of the most recent report(s) which you submitted.

4. Please enclose a copy of the criteria and method by which you evaluate agencies, boards, etc. If this is not available, please explain same below:

js
8-15-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY: School of Education, University of Wisconsin - Milwaukee
Dr. Adrian Chan (Principal Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.

FUNDED BY: Wisconsin Council on Developmental Disabilities.

We are currently conducting a project for the Wisconsin Council on Developmental Disabilities to explore the area of advocacy for the developmentally disabled. We are interested in your perceptions of advocacy, its need, its possible programmatic implementation and its problems. Specifically, we are asking individuals and voluntary groups and agencies, on all levels, their perspectives relating to this matter.

All information gathered will be confidential and coded to protect the source (individual, group or agency) so that it cannot be used by others. The information gathered by this survey will be used for estimating the need, function, structure and linkages of advocacy programs for the developmentally disabled in Wisconsin. The questionnaire is not an evaluation of rehabilitation agencies. It is simply an instrument that will enable us to formulate an overview of services for the developmentally disabled in Wisconsin.

Please return the questionnaire in the self-addressed envelope provided, after completion.

js
8-14-75

DEVELOPMENTAL DISABILITIES

51.42/51.437 BOARD QUESTIONNAIRE

-I-

INTERNAL CONSTITUTION

(PLEASE PRINT OR TYPE ALL ANSWERS.)

1. Person(s) completing questionnaire:

name	title	phone
name	title	phone

2. Name of Board: ______________________________

3. How often does the board meet: (check one)

__ Only when necessary.

__ Once a week.

__ Once every two weeks.

__ Once a month.

__ Other: ______________________________ please specify

INTERNAL CONSTITUTION

4. Please provide the following information regarding the membership of your board: (Please print or type.)

Name	Occupation	Sex	Approximate Age	Racial-Ethnic Background*	Developmentally Disabled?**	Relationship to Develop. Disabled person.***	Phone
(Chairman)							

* Enter the proper number: 1. Black -- 2. White -- 3. American Indian -- 4. Latin -- 5. Asian-American -- 6. Other.

** Enter the proper letter: Y = Yes; N = No.

*** Enter the proper number: 1. Parent -- 2. Sibling -- 3. Aunt or Uncle -- 4. Other -- 5. None.

BOARD QUESTIONNAIRE

-II-

BUDGET

1. Who allocates funds directly to your board? (check all that apply -- indicate approximate/exact (circle one) percentage from which source -- name agency(ies)).

__ Federal Agency(ies): _____% a) ____________________
name(s)
b) ____________________
c) ____________________

__ State Agency(ies): _____% a) ____________________
b) ____________________
c) ____________________

__ Private Foundations: _____% a) ____________________
b) ____________________
c) ____________________

__ Other: _____% a) ____________________
b) ____________________
c) ____________________

2. Who audits the expenditure of funds that the board has allocated to local community agencies?

Name	Title	Agency

3. What legislative and outside administrative sources have been of most assistance to the board? (check all that apply -- circle those that have been most helpful.)

___ Wisconsin Statutes

___ Wisconsin Administrative Code

___ The State Plan for the Developmental Disabilities Act.

___ U.S. Code

___ Code of Federal Regulations

___ County Corporation Counsel

___ Area-wide Comprehensive Health Planning Agency ("B" Board)

___ Division of Health Policy and Planning

___ 51.42 Board

___ 51.437 Board

___ Developmental Disabilities Board

___ Department of Public Instruction

___ Division of Mental Health

___ Division of Vocational Rehabilitation

___ Division of Family Services

___ Other: ______________________________
please indicate
____

4. What percentage and/or amount of your funds during fiscal year '74 (i.e., 7/1/74 - 6/30/75) and fiscal year '75 (i.e., 7/1/75 - 6/30/76) have been allocated for each of the service areas indicated below:

Service Areas	Past Fiscal Year		Present Fiscal Year	
	% and/or	$	% and/or	$
1. Evaluation:				
2. Diagnosis:				
3. Treatment:				
4. Day Care:				
5. Training:				
6. Education:				
7. Sheltered Employment:				
8. Personal Care:				
9. Domiciliary Care:				
10. Special Living Arrangements:				
11. Information and Referral:				
12. Counseling:				
13. Follow-along:				
14. Protective:				
15. Recreation:				
16. Transportation:				

5. How do members of your board achieve membership? (check one and complete response)

__ Elected -- By Whom: ____________________

__ Appointed -- By Whom: ____________________

__ Other: ____________________

BOARD QUESTIONNAIRE

-III-

CONTACT WITH OTHER AGENCIES, BOARDS, ETC.

1. Is there a 51.42/51.437 Board in your area of jurisdiction? (check one -- if no, proceed to question 2).

__ Yes, __ No.

If Yes: Do you communicate with this Board? (check one)

__ Weekly

__ Monthly

__ Approximately once every six months

__ Other: ______________________

1.1 Please explain the benefits or problems which occrue to your area of jurisdiction as a result of having two boards with overlapping statutory responsibilities?

Benefits	Problems

2. If a recipient of a service for which you are responsible has a problem which you cannot solve within the board, to whom do you go for advice? (check all that apply -- if more than one, circle the one used most freqeuncly.)

__ County Corporation Counsel

__ Area-wide Comprehensive Health Planning Agency ("B" Board)

__ 51.42 Board

__ 51.437 Board

__ Developmental Disabilities Board

__ Department of Public Instruction

__ Division of Mental Health

__ Division of Vocational Rehabilitation

__ Division of Family Services

__ Other: ____________________

____

____

3. What agencies do you regulate? (Please check and attach a list if the space provided is not adequate.)

___ All the agencies which you fund.

___ Other: ______________________________

____

3.1 How do you evaluate the quality of the services these agencies perform? (check all that apply.)

___ Verbal reports

___ Written reports

___ Scheduled on-site visits

___ Unscheduled on-site visit

___ Investigation of client complaints

___ Outside evaluator

___ Other: ______________________________
please specify

3.2 How often do you evaluate these agencies? (check all that apply.)

___ Monthly

___ Quarterly

___ Semi-annually

___ Annually

___ Other: ______________________________

4. What agency is primarily responsible for regulating your board?

____

4.1 How does this agency evaluate your board?

____

____

____

4.2 How often are you evaluated by this agency? (check all that apply.)

___ Monthly

___ Quarterly

___ Semi-annually

___ Annually

___ Other: ______________________________

5. List any agencies serving developmentally disabled citizens in your geographic area of jurisdiction which you do not regulate.

1. ______________________________

2. ______________________________

3. ______________________________

4. ______________________________

5. ______________________________

BOARD QUESTIONNAIRE

-IV-

ADVOCACY

1. Define advocacy as you perceive it.

   Uncertain: ____

2. If your board has ever expressed its perception of advocacy, please describe it.

3. What do you see as the goals of advocacy services with developmentally disabled clients?

   Uncertain: ____

4. What do you see as the differences between advocacy and protective services?

   Uncertain: ____

5. In which of the sixteen service categories do you think advocacy services are most needed? (check all that apply -- circle "most needed" category.)

Diagnosis: _____
Evaluation: _____
Treatment: _____
Personal Care: _____
Day Care: _____
Domiciliary Care: _____
Special Living Arrangements: _____
Training: _____
Education: _____
Follow-along: _____
Sheltered Employment: _____
Recreation: _____
Counseling: _____
Protective Sociolegal: _____
Information Referral: _____
Transportation: _____

6. In addition to the above sixteen service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

Uncertain: _____

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services? (check all that apply -- circle group most in need.)

_____ Cerebral Palsy (specify age group: _____)
_____ Mentally retarded (specify age group: _____)
_____ Epileptics (specify age group: _____)
_____ Multiple impairment (specify age group: _____)
_____ Others (specify age group: _____)
_____ None of above groups (reasons given: ____________________
____)

8. Briefly describe what you believe to be the optimum administrative location and funding source for advocacy programs.

____

____

____

Uncertain: _____

9. Have you received information concerning outside agencies willing to fund advocacy efforts? (check one.)

__ Yes __ No.

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? (please list.)

____

____

____

10. What agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in your geographical area of jurisdiction? (please list names, addresses, etc. if possible. Attach list if space provided is not adequate.)

a. ______________________________

b. ______________________________

c. ______________________________

d. ______________________________

Uncertain: _____

11. What other groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in initiating advocacy services? (please list and state how these might be cooperative/facilitative.)

____

____

____

Uncertain: _____

12. Do you currently regulate/fund any advocacy programs?

__ Yes __ No.

If Yes, answer questions 15 through 19.

If No, answer questions 13 through 19.

13. If you and your board were to initiate advocacy services, briefly describe what you believe to be the optimum administrative location and funding source for such programs under your jurisdiction.

____

____

____

Uncertain: _____

14. What problems do you face if you were to initiate such advocacy services? (administrative, personnel, financial, etc.)

____

____

____

Uncertain: _____

15. What is the source of those funds for your advocacy programs?

16. How does your board ensure that services to developmentally disabled citizens served by agencies are the "least possible restrictive" on their personal liberties?

17. How often did developmentally disabled clients or their representatives present the board with a grievance during the past twelve months? (check one and indicate number.)

__ Exactly: _____

__ Approximately: _____

18. What are the most common types of developmentally disabled client grievances that come to your board?

a. ______

b. ______

c. ______

19. If your board is unable to resolve a grievance from developmentally disabled clients or their representatives, what do you do?

APPENDIX I

DOCUMENTS

1. Are minutes/transcripts kept of board meetings: (check one)

   __ Yes; __ No.

   If Yes: Please send us copies of those documents pertaining to the last two meetings.

2. Please enclose a copy of your by-laws and operating procedures (including any client grievance procedures) with this completed questionnaire. If these are not available, please describe the board's responsibility and authority.

   ____

   ____

   ____

3. Please send us a copy of the last fiscal year's allocation if available. If it is not abailable, to whom does your board allocate funds? (Please indicate name of agency and percentage of total allocated and/or amount for each agency -- attach a list if space provided is not adequate.)

   1. ______________ $ ________ and/or ________ %
   2. ______________ $ ________ and/or ________ %
   3. ______________ $ ________ and/or ________ %
   4. ______________ $ ________ and/or ________ %
   5. ______________ $ ________ and/or ________ %

4. If you have documents regarding funding criteria, priority areas, standards for acceptance or rejection of requests for funds, etc., please enclose them with this questionnaire. If not, please describe such criteria below:

   ____

   ____

   ____

   ____

5. Please enclose a copy of the criteria which you use to evaluate agencies. If this is not available, please explain below:

____

____

____

6. If you are required to conform to a formal reporting mechanism, please enclose a copy of the most recent report(s) which you submitted.

js
8-14-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROJECT

CONDUCTED BY:	SCHOOL OF EDUCATION, UNIVERSITY OF WISCONSIN-MILWAUKEE DR. ADRIAN CHAN (PRINCIPAL INVESTIGATOR), PAT GARLAND, MIKE BROPHY AND PAT LINNANE (414) 963-4798.
FUNDED BY	WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES

____

____

WE ARE CURRENTLY CONDUCTING A PROJECT FOR THE WISCONSIN COUNCIL ON DEVELOPMENTAL DISABILITIES TO EXPLORE THE AREA OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED. WE ARE INTERESTED IN YOUR PERCEPTIONS OF THE PROBLEMS FACED AND THE SOLUTIONS OFFERED THE DEVELOPMENTALLY DISABLED.

AS WITH ALL INFORMATION WE GATHER YOUR ANSWERS WILL BE CONFIDENTIAL AND CODED TO PROTECT THEIR SOURCE. THE INFORMATION GATHERED BY THIS SURVEY WILL BE USED FOR ESTIMATING THE NEED FUNCTION STRUCTURE AND AFFILIATIONS OF ADVOCACY PROGRAMS FOR THE DEVELOPMENTALLY DISABLED IN WISCONSIN

INDIVIDUAL QUESTIONNAIRE

NAME: ______________________________ DATE: ______________

AGE: __________

TYPE OF DEVELOPMENTAL DISABILITY:

_____ EPILEPSY

_____ MENTAL RETARDATION

_____ CEREBRAL PALSY

_____ MULTIPLE DISABILITY (PLEASE LIST)

____

____

____

____

PLACE OF RESIDENCE:

_____ HOME

_____ NURSING HOME

_____ OTHER: ______________________________
(PLEASE LIST)

DO YOU RECEIVE DAY CARE SERVICES: _____ YES _____ NO

AGENCY PRESENTLY PROVIDING SERVICES TO YOU. ______________________
(NAME OF AGENCY)

QUESTIONNAIRE ANSWERED BY:

_____ INDIVIDUAL

_____ FAMILY

_____ FRIEND

_____ GUARDIAN

_____ OTHER ______________________________
(PLEASE INDICATE RELATIONSHIP TO INDIVIDUAL)

1. WHAT ACTIVITIES DO YOU LIKE? (PLEASE CHECK ( ) THOSE ACTIVITIES)

____ HOBBIES

____ GAMES

____ SPORTS

____ READING

____ MUSIC

____ TRAVEL

____ T.V. and/or RADIO

____ MOVIES

____ OTHERS: ______________________________
(PLEASE LIST) ______________________________

2. DO YOU HAVE A CHANCE TO DO SOME OF THESE THINGS? ____ YES ____ NO

IF YES, HOW OFTEN?

____ MORE THAN ONCE A WEEK

____ ONCE A WEEK

____ ONCE EVERY TWO WEEKS

____ ONCE A MONTH

____ LESS THAN ONCE A MONTH

DO YOU DO SOME OF THESE THINGS WITH OTHERS? ____ YES ____ NO

IF YES, WITH WHOM?

____ FAMILY

____ FRIENDS

____ OTHERS: ______________________________
(PLEASE LIST) ______________________________
____

3. WHAT DO YOU WANT THIS AGENCY TO DO MORE OF?

(PLEASE LIST) ______________________________
____
____
____
____
____

4. WHAT DO YOU WANT THIS AGENCY TO DO LESS OF?

(PLEASE LIST)

5. WHAT DO YOU WANT THIS AGENCY TO DO FOR YOU PERSONALLY, (OR FOR THE PERSON FOR WHOM YOU ARE RESPONSIBLE?)

(PLEASE LIST)

6. WHAT DO YOU WANT TO DO IN YOUR LIFE? WHAT ARE YOUR AMBITIONS (OR YOUR AMBITIONS FOR THE PERSON FOR WHOM YOU ARE RESPONSIBLE?)

(PLEASE LIST)

7. WHAT KINDS OF THINGS DO YOU DO BY YOURSELF?

____ A) GET UP/WASH/DRESS
____ B) FIX SOMETHING TO EAT
____ C) GO SOMEPLACE OUTSIDE
____ D) BUY THINGS

E) ____________
(PLEASE FILL IN REST)
F) ____________
G) ____________
H) ____________

8. WHAT KINDS OF THINGS CAN YOU DO BY YOURSELF WITH SOME HELP FROM OTHERS?

____ A) GET UP/WASH/DRESS E) ____________________
(PLEASE FILL IN REST)
____ B) FIX SOMETHING TO EAT F) ____________________
____ C) GO SOMEPLACE OUTSIDE G) ____________________
____ D) BUY THINGS H) ____________________

9. WHAT KINDS OF THINGS DO YOU HAVE OTHERS DO FOR YOU?

____ A) GET UP/WASH/DRESS E) ____________________
(PLEASE FILL IN REST)
____ B) FIX SOMETHING TO EAT F) ____________________
____ C) GO SOMEPLACE OUTSIDE G) ____________________
____ D) BUY THINGS H) ____________________

10. IF YOU HAVE OTHER PEOPLE HELP YOU, WHO ARE THEY?

____ FAMILY
____ FRIENDS
____ GUARDIAN
____ SOCIAL AGENCY: ____________________
(NAME OF AGENCY)
____ OTHER(S): ____________________
(PLEASE LIST)
____

11. ARE MOST OF YOUR PROBLEMS SOLVED THE WAY YOU WANT THEM TO BE SOLVED?

____ YES ____ NO IF NO, CAN YOU CITE ANY REASONS WHY NOT?

____
(PLEASE LIST)
____
____
____
____

12. WHAT PROBLEMS DO YOU HAVE WHEN YOU GO FOR HELP? (PLEASE CHECK ( ) THOSE PROBLEMS.)

SOMEONE MAKING A MISTAKE ABOUT:

____ A) WHAT TYPE OF DISABILITY YOU HAVE

____ B) WHAT YOU ARE ABLE TO DO (JOB, SCHOOL, ETC.)

____ C) TELLING YOU WHAT TO DO FOR YOUR PROBLEMS

I AM NOT HAPPY WITH

____ D) FOOD I RECEIVE

____ E) WHERE I LIVE

____ F) CLOTHING

____ G) EQUIPMENT (WHEELCHAIRS, ETC.)

____ H) TALKING AND DOING THINGS WITH OTHER PEOPLE

WHY? ____
(PLEASE LIST)
____
____

____ I) NOT BEING TAUGHT MY JOB

____ J) NOT BEING TAUGHT SKILLS LIKE READING, WRITING, ETC.

____ K) NOT BEING ABLE TO GET A FULL OR PART TIME JOB IN A REHABILITATION AGENCY.

____ L) COUNSELING

____ M) THE HELP I GET IN UNDERSTANDING THE LAW ABOUT WHAT RIGHTS I HAVE

____ N) TRANSPORTATION

____ O) OTHER PROBLEMS: ________________________________
(PLEASE LIST)
____
____
____
____

13. HAVE YOU EVER FOUND THAT WHEN YOU RECEIVED HELP FROM A SOCIAL SERVICE AGENCY THAT IT CAUSED YOU OTHER PROBLEMS?

____ YES ____ NO

IF YES PLEASE EXPLAIN ______________________________

NOTES: (PLEASE DO NOT WRITE BELOW THIS DOUBLE LINE!)

js
8-4-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY:	School of Education, University of Wisconsin - Milwaukee Dr. Adrian Chan (Pringiple Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.
FUNDED BY:	Wisconsin Council on Developmental Disabilities.

We are currently conducting a project for the Wisconsin Council on Developmental Disabilities to explore the area of advocacy for the developmentally disabled. We are interested in your perceptions of advocacy, its need, its possible programmatic implementation and its problems. Specifically, we are asking individuals and voluntary groups and agencies, on all levels, their perspectives relating to this matter.

This questionnaire is divided into three sections. Please complete Section I. Then if you have an advocacy program, please complete Section II. If you do not have an advocacy program, ignore Section II and complete Section III.

All information gathered will be confidential and coded to protect the source (individual, group or agency) so that it cannot be used by others. The information gathered by this survey will be used for estimating the need, function, structure and linkages of advocacy programs for the developmentally disabled in Wisconsin. The questionnaire is not an evaluation of rehabilitation agencies. It is simply an instrument that will enable us to formulate an overview of services for the developmentally disabled in Wisconsin.

js
7-22-75

DATE: ____________

Person completing questionnaire: ______________________________

Position in agency: ______________________________

Name of Program or Agency: ______________________________

Location(s): ______________________________

What is your agency's geographic coverage?

City: ____ County: ____ State: ____

Number of years operating in present capacity?

Less than 1 yr: ____ 1 yr: ____ 2 yrs: ____ 2 yrs +: ____

STRUCTURE

1. Total No. of Staff: ________

	Full Time	Part Time
2. Number of Professional Staff:	________	________
Number of Para-professional Staff:	________	________
Number of Volunteers:	________	________

3. What type of groups do you serve? Please state numerically.

	Institutionalized	Non-Institutionalized
Developmentally Disabled (Mental Retardation, Cerebral Palsy, Epilepsy):	________	________
Emotionally Disturbed:	________	________
Multiply Handicapped:	________	________

4. Generally, how much of your agency's time and money are devoted to the following?

____% - Direct care service time

____% - Indirect care service time

____% - Administrative time

____% - Direct care service

____% - Indirect care service money

____% - Administrative money

5. Please list the objectives of your program or please provide us with written material stating your agency's objectives (i.e., brochures, etc.)

____

____

____

____

6. How are you funded? _____% - Public _____% - Private.

7. What services does your agency provide? In those service areas that you indicate, also indicate whether the population served is of heavy, moderate or light volume.

Diagnosis:	*H__M__L__	Education:	H__M__L__
Evaluation:	H__M__L__	Sheltered Employment:	H__M__L__
Treatment:	H__M__L__	Recreation:	H__M__L__
Personal Care:	H__M__L__	Counseling:	H__M__L__
Day Care:	H__M__L__	Protective Sociolegal:	H__M__L__
Residential Care:	H__M__L__	Information & Referral:	H__M__L__
Special living Arrangements:	H__M__L__	Follow-Along	H__M__L__
Training:	H__M__L__	Transportation:	H__M__L__

*H=Heavy; M=Moderate; L=Light.

8. How does your agency determine what is the least restrictive and most appropriate service (in light of recent Supreme Court rulings) for the developmentally disabled client?

____

____

____

____

____

9. Briefly, what services does your agency contract for?

Recipient of Contract

Psychological testing: ____________________

Vocational testing: ____________________

Sheltered employment: ____________________

Other: ____________________ ____________________

____________________ ____________________

____________________ ____________________

____________________ ____________________

10. Briefly, what services do other agencies contract for with you?

Contracting Agency

Psychological testing: ____________________

Vocational testing: ____________________

Sheltered Employment: ____________________

Other: ____________________ ____________________

____________________ ____________________

____________________ ____________________

____________________ ____________________

AFFILIATIONS

1. Generally, what types of working agreements with government agencies have been basic to your operation?

____

____

____

____

____

2. Which government agencies have you found to be most helpful?

____

____

____

____

____

3. Do you (Director, Assistant Director) hold seats (voting or non-voting) on committees or boards of other agencies?

Yes: _____ No: _____

If Yes, please list:

a: ________________ b: ______________________

c: ________________ d: ______________________

e: ________________ f: ______________________

4. What conditions do you see as having contributed most to the success of your program? Please list briefly:

a: ________________ b: ______________________

c: ________________ d: ______________________

e: ________________ f: ______________________

5. Are there any factors which have limited the conditions of your program? (Please check)

	Past	Present
Financial:	_____	_____
Legal:	_____	_____
Bureaucratic:		
[illegible]:	_____	_____
Staff (quality):	_____	_____
Staff (quantity):	_____	_____

(Question continued next page.)

5. (Continued from previous page.)

Others: a: ______________________________

b: ______________ c: ______________

d: ______________ e: ______________

f: ______________ g: ______________

FUNCTION

1. What is the total number of people you have served in the past calendar year? (Estimate if exact number is difficult to obtain.)

Grand Total: ________

2. What major factors affect the volume and nature of client contacts:

Financial: ____

Agency Size (Physical property): ____

Referrals: ____

Agency Size (Staff population): ____

Geographic Location: ____

Other: a: ______________________________

b: ______________ c: ______________

d: ______________ e: ______________

f: ______________ g: ______________

3. Do you employ any forms of outreach?

Yes: ____ No: ____

T.V.: ____ Brochures: ____

Press: Speaking Engagements:

Other: ______________________________

____

____

4. How does your agency make its determination as to which individuals are in need of your services and which are not?

Referrals: ____

Testing: ____

Geographic proximity of
client's residence to agency: ____

Other: (please specify) a: ____________

b: ____________ c: ____________

d: ____________ e: ____________

5. Generally, what methods are employed to monitor the client's progress?

Within the agency: a: ____________

b: ____________ c: ____________

d: ____________ e: ____________

On the job placement: a: ____________

b: ____________ c: ____________

d: ____________ e: ____________

Other: a: ____________

b: ____________ c: ____________

d: ____________ e: ____________

SECTION II

FOR THOSE AGENCIES WITH ADVOCACY SERVICES

(If you do not have advocacy services, do not answer the questions in Section II. Move directly to Section III.)

1. Define advocacy as it is performed by your agency.

____

____

____

____

____

2. What do you see as the goals of advocacy services in your agency?

____

____

____

____

____

3. What do you see as the differences between advocacy and protective services? (As in Wisconsin Statutes, Chapter 284 (1973))

____

____

____

____

____

____

____

____

4. Approximately what percent of your entire agency program is devoted to advocacy efforts:

_____% of staff; _____% of budget; _____% of time.

5. How many persons do you have performing advocacy services: _______

Approximately, what is the turnover rate for your advocates within the last six (6) months?

0-10% _____; 11-20% _____; 21-30% _____; 31-40% _____;

41-50% _____; 51-60% _____; over 61% _____.

6. The average number of hours per week performed by these advocates is _____.

7. Advocacy services are provided for which of the sixteen (16) protective service categories?

Diagnosis: _____

Evaluation: _____

Treatment: _____

Personal Care: _____

Day Care: _____

Comiciliary Care: _____

Special Living Arrangements: _____

Training: _____

Education: _____

Follow-Along: _____

Sheltered Employment: _____

Recreation: _____

Counseling: _____

Protective Sociolegal: _____

Information Referral: _____

Transportation: _____

8. In addition to the above sixteen service categories, do your advocates perform other services, roles, tasks, etc.?

a: ____________________ b: ____________________

c: ____________________ d: ____________________

e: ____________________ f: ____________________

g: ____________________ h: ____________________

9. Those individuals performing advocacy roles are selected from inside/outside your agency. (circle one or both)

10. If your advocates are selected from outside of your agency, from what background and locality do you select them?

____

____

____

____

____

11. In addition, other characteristics of those performing advocate roles are generally:

_____% - males; _____% - females.

Estimated average age of advocates: _____ years.

Estimated average educational level: _____ years.

_____% - Volunteers.

_____% - Paid staff: Estimated average pay: __________

Estimated basis of pay scale:

Amount of time with agency: _____

Amount of time with advocacy: _____

Position within agency: _____

Educational level: _____

Other: ____

____

____

_____% - Blacks; _____% - Latins; _____% - Native Americans;

_____% - Asians; _____% - Whites.

12. If you have a training program for your advocates, please explain it briefly in terms of orientation, skills taught, length, supervision, etc.

13. How does your agency determine whether or not a client needs your advocacy services?

14. Please estimate the number and respective average ages of those clients served by your advocacy program.

	Number	Average age
Cerebral Palsy clients:		
Mentally Retarded clients:		
Epileptic clients"		
Multiply Impaired clients:		
Other clients:		

If others, please specify: ____________________

15. Are those needs which are expressed by the developmentally disabled client or his family the same as those found in the sixteen protective service categories? (See page 8.) If not, what specific client needs are unanswered and are amenable to advocacy roles?

16. What types of records are kept on the clients receiving advocacy services?

17. Please estimate loosely what percentage of the clients receiving your advocacy services are capable of the following? (Total = 100%)

a. _____% of developmentally disabled clients capable of solving their own problems without assistance.

b. _____% of developmentally disabled clients capable of solving their own problems with some guidance and instruction.

c. _____% of developmentally disabled clients capable of solving their own problems with maximal guidance and instruction.

d. _____% of developmentally disabled clients relying on advocates somewhat to solve problems for them.

e. _____% of developmentally disabled clients relying on advocates heavily to solve problems for them.

f. _____% of developmentally disabled clients relying on advocates completely to solve problems for them.

18. What types of feedback/evaluation efforts are undertaken on the advocacy services performed by your agency?

19. What kinds of problems are faced by your agency in providing advocacy services? (administrative, personnel, financial, etc.)

20. How are your present advocacy efforts funded? Please cite source.

21. Have you received information concerning outside agencies willing to fund advocacy efforts:

Yes _____; No _____

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? Please list.

____

____

____

22. What other agencies, groups or individuals do you know of, which also perform advocacy services for developmentally disabled clients in Wisconsin? Please list names, addresses, etc. if possible.

____

____

____

____

____

____

23. What groups, boards, agencies (local, regional, state) have been cooperative and facilitative in helping you achieve your advocacy service goals? How have they been cooperative/facilitative?

____

____

____

____

____

____

____

____

SECTION III

FOR THOSE AGENCIES WITHOUT ADVOCACY SERVICES

((If you have advocacy services, please respond to Section II and ignore Section III.)

1. Define advocacy as you perceive it and as your agency perceives it.

Uncertain: ____

2. What do you see as the goals of advocacy services with developmentally disabled clients?

Uncertain: ____

3. What do you see as the differences between advocacy and protective services?

Uncertain: ____

4. Which of the sixteen service categories do you think advocacy services are most needed in?

Diagnosis: _____

Evaluation: _____

Treatment: _____

Personal Care: _____

Day Care: _____

Domiciliary Care: _____

Special Living Arrangements: _____

Training: _____

Education: _____

Follow-Along: _____

Sheltered Employment: _____

Recreation: _____

Counseling: _____

Protective Sociolegal: _____

Information Referral: _____

Transportation: _____

5. In addition to the above sixteen service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

____

Uncertain: _____

6. Are the expressed needs of the developmentally disabled clients the same as the above sixteen service categories? If not, what specific client needs are unanswered and are amenable to advocacy roles?

____

____

____

____

____

Uncertain: _____

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services?

_____ Cerebral Palsy (specify age group: __________)

_____ Mentally retarded (specify age group: __________)

_____ Epileptics (specify age group: __________)

_____ Multiple impairment (specify age group: __________)

_____ Others (specify age group: __________)

_____ None of above group (reasons given: ____________________

____)

8. If you and your agency were to set up advocacy services, briefly describe how you might select and maintain individuals performing advocacy services. (Selection factors, preference for paid or volunteer program, etc.)

____

____

____

____

____

Uncertain: _____

9. If you and your agency were to set up an advocacy component, what might you include in your training/inservice program for individuals performing advocacy roles? (orientation, skills taught, length, supervision, etc.)

____

____

____

____

____

Uncertain: _____

10. How might your agency determine whether or not clients are in need of advocacy services?

____

____

____

____

Uncertain: _____

11. If you were to initiate advocacy services, please estimate loosely what percent of clients receiving these services are capable of doing the following: (total = 100%)

a. _____% of developmentally disabled clients capable of solving their own problems without assistance.

b. _____% of developmentally disabled clients capable of solving their own problems with some guidance and instruction.

c. _____% of developmentally disabled clients capable of solving their own problems with maximal guidance and instruction.

d. _____% of developmentally disabled clients relying on advocates somewhat to solve problems for them.

e. _____% of developmentally disabled clients relying on advocates heavily to solve problems for them.

f. _____% of developmentally disabled clients relying on advocates completely to solve problems for them.

12. What problems do you face if you were to set up such advocacy services in your agency? (administrative, personnel, financial, etc.)

____

____

____

____

____

Uncertain: _____

13. Have you received information concerning outside agencies willing to fund advocacy efforts?

Yes _____; No _____

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? Please list.

____

____

____

____

Uncertain: _____

14. What other agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in Wisconsin? Please list names, adresses, etc. if possible.

____

____

____

____

____

Uncertain: _____

15. What groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in setting up advocacy services in your agency? Please list and state how these might be cooperative/facilitative.

____

____

____

____

____

Uncertain: _____

js - 7-17-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY:	School of Education, University of Wisconsin - Milwaukee Dr. Adrian Chan (Principal Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.
FUNDED BY:	Wisconsin Council on Developmental Disabilities.

We are currently conducting a project for the Wisconsin Council on Developmental Disabilities to explore the area of advocacy for the developmentally disabled. We are interested in your perceptions of advocacy, its need, its possible programmatic implementation and its problems. Specifically, we are asking individuals and voluntary groups and agencies, on all levels, their perspectives relating to this matter.

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Please return the questionnaire in the self-addressed envelope provided, after completion.

js
8-14-75

[illegible]

ADMINISTRATIVE AGENCY* QUESTIONNAIRE

-I-

INTERNAL CONSTITUTION

(PLEASE PRINT OR TYPE ALL ANSWERS.)

1. Person(s) completing questionnaire:

name	title	phone
name	title	phone

2. Title of Agency: ______________________________

---

* For the purposes of this questionnaire, the term "agency" includes division, council, bureau, etc.

INTERNAL CONSTITUTION

[illegible]. Please provide the following information regarding those employees of your agency who are assigned to work relating to 51.42/51.437 boards. (please print or type.)

Name	Job Title	Sex	A[illegible]	[illegible]ate [illegible]cial- Bac[illegible]	[illegible]elopmentally Disabled	Number of years employed in this agency.	[illegible] time assigned [illegible] work with 51.42 b[illegible]	% of time assigned work with [illegible] boards.	[illegible]	[illegible]

* Enter the proper number(s): 1. Black -- 2. White -- 3. American Indian -- 4. Latin -- 5. Asian-American -- 6. Other.

* Enter the proper letter: Y = Yes; N = No.

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-II-

BUDGET

1. What are the sources of your funds for developmental disabilities during this fiscal year, i.e., 7/1/75 - 6/30/76? (Indicate name of source and amount and/or percent of total.)

$ and/or %
source

$ and/or %
source

$ and/or %
source

$ and/or %
source

2. To whom does your agency allocate funds? (Indicate name of agency and percentage of total allocated and/or amount for each agency. If space provided is not adequate, please attach a list.)

$ and/or %
source

$ and/or %
source

$ and/or %
source

$ and/or %

3. What legislative and administrative sources outside of your agency have been most helpful to you when questions relating to fiscal policy arise? (Please check all that apply and circle those which have been most helpful.)

___ U.S. Code
___ Code of Federal Regulations
___ Wisconsin Statutes
___ Wisconsin Administrative Code
___ Developmental Disabilities Act.
___ County Corporation Counsel
___ Area-wide Comprehensive Health Planning Agency (B Board)
___ Division of Health Policy and Planning
___ 51.42 Board
___ Developmental Disabilities Board
___ Department of Public Instruction

(Cont'd. next page)

3. Cont'd. from page 3.

__ Division of Mental Health　　__ Division of Vocational Rehabilitation

__ Division of Family Services

__ Other: ______________________________
please indicate

____

4. What percentage and/or amount of your funds for fiscal '74 (i.e., 7/1/74 - 6/30/75) and fiscal '75 (i.e., 7/1/75 - 6/30/76) were designated for each of the service areas listed below:

Service Areas	Past Fiscal Year		Present Fiscal Year	
	%	and/or $	%	and/or $
1. Evaluation:				
2. Diagnosis:				
3. Treatment:				
4. Day Care				
5. Training:				
6. Education:				
7. Sheltered Employment:				
8. Personal Care:				
9. Domiciliary Care:				
10. Special Living Arrangements:				
11. Information and Referral:				
12. Counseling:				
13. Follow-along:				
14. Protective:				
15. Recreation:				
16. Transportation:				

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-III-

CONTACT WITH OTHER AGENCIES

1. List the administrative agencies and boards with whom you have formal contact regarding developmental disabilities. (List agencies and number designating kind(s) of relationship(s).*)

Agencies	Relationship*
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other
______________________	/ / / / ______________ other

* Enter the proper numbers and/or explanation under Relationship as follows: 1. Funding -- 2. Evaluation -- 3. Consultation -- 4. Planning -- 5. Other.

2. What agencies with responsibilities in the area of developmental disabilities do you regulate? (check all that apply -- Please attach a list if the space provided after "other" is not adequate.)

__ All the agencies which you fund.

__ Other: ______________________________

____

____

2.1 How often do you evaluate these agencies? (check all that apply

__ [illegible] __ [illegible]

__ Quarterly __ Annually

__ Other: ______________________________
please specify

2.2 What do you do with the results of the evaluation?

____

____

____

3. How and by whom is your agency evaluated?

____

____

____

4. How often are you evaluated? (check all that apply.)

__ Monthly
__ Quarterly
__ Other: ______________________________
please explain

__ Semi-annually
__ Annually

ADMINISTRATIVE AGENCY QUESTIONNAIRE

-IV-

ADVOCACY

1. Define advocacy as you perceive it.

   Uncertain: _____

2. If your agency has ever expressed its perception of advocacy, please describe it.

3. What do you see as the goals of advocacy services with developmentally disabled clients?

   Uncertain: _____

4. What do you see as the differences between advocacy and protective services?

   Uncertain:

5. In which of the above service categories do you think advocacy services are most needed? (check all that apply -- circle "most needed" category.)

Diagnosis: ____

Evaluation: ____

Treatment: ____

Personal Care: ____

Day Care: ____

Domiciliary Care: ____

Special Living Arrangements: ____

Training: ____

Education: ____

Follow-along: ____

Sheltered Employment: ____

Recreation: ____

Counseling: ____

Protective Sociolegal: ____

Information Referral: ____

Transportation: ____

6. In addition to the above service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

Uncertain: ____

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services? (check all that apply -- circle group most in need.)

__ Cerebral Palsy (specify age group: ________)

__ Mentally retarded (specify age group: ________)

__ Epileptics (specify age group: ________)

Multiple impairment (specify age group: ________)

__ Others (specify age group: ________)

__ None of the above groups (reasons given: ________________

____)

8. Briefly, describe what you believe to be the optimum administrative location and funding source for advocacy programs.

____

____

____

Uncertain: _____

9. Have you received information concerning outside agencies willing to fund advocacy efforts? (check one.)

__ Yes __ No.

If Yes: Please list those with which you are familiar:

____

____

____

10. What agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in your geographical area of jurisdiction? (Please list names, addresses, etc. if possible. Utilize back if space provided is not adequate.)

a. ____

b. ____

c. ____

d. ____

e. ____

11. What other groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in initiating advocacy services? (please list ans state how these might be cooperative/

____

____

Uncertain: _____

12. Do you currently regulate/fund any advocacy programs?

___ Yes ___ No.

If Yes, answer questions 15 through 19.

If No, answer questions 13 through 19.

13. If your agency was to initiate advocacy services, briefly describe what you believe to be the optimum administrative location and funding source for such programs under your jurisdiction.

____

____

____

14. What problems do you face if you were to initiate such advocacy services? (administrative, personnel, financial, etc.

____

____

____

15. What is the source of funds for your advocacy program(s)?

____

____

____

16. How does your agency ensure that services to developmentally disabled citizens served by agencies are the "least possible restrictive" on their personal liberties?

____

____

____

17. How often did developmentally disabled clients or their representatives present your agency with a grievance during the past twelve months? (check one and indicate number.)

___ Exactly: _____

___ Approximately: _____

18. What are the most common types of developmentally disabled client grievances that come to your agency?

a. ______________________________

b. ______________________________

c. ______________________________

19. If your agency is unable to resolve a grievance from developmentally disabled client or their representative, what do you do?

____

____

____

APPENDIX I

DOCUMENTS

1. Please enclose a copy of your by-laws and operating procedures with this completed questionnaire. If this is not available, please describe your responsibility and authority below:

____

____

____

2. If you have documents regarding funding criteria, priority areas, standards for acceptance or rejection of requests for funds, etc., please enclose them with this questionnaire. If not, please describe such criteria below:

____

____

____

3. If you are required to conform to a formal reporting mechanism, please enclose a copy of the most recent report(s) which you submitted.

4. Please enclose a copy of the criteria and method by which you evaluate agencies, boards, etc. If this is not available, please explain same below:

____

____

____

js
8-15-75

DEVELOPMENTAL DISABILITIES

ADVOCACY SURVEY PROGRAM

CONDUCTED BY:	School of Education, University of Wisconsin - Milwaukee Dr. Adrian Chan (Principal Investigator), Pat Garland, Mike Brophy and Pat Linnane (414) 963-4798.
FUNDED BY:	Wisconsin Council on Developmental Disabilities.

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js
8-14-75

5

DEVELOPMENTAL DISABILITIES

51.42/51.437 BOARD QUESTIONNAIRE

-I-

INTERNAL CONSTITUTION

(PLEASE PRINT OR TYPE ALL ANSWERS.)

1. Person(s) completing questionnaire:

name	title	phone
name	title	phone

2. Name of Board: ______________________________

3. How often does the board meet: (check one)

__ Only when necessary.
__ Once a week.
__ Once every two weeks.
__ Once a month.
__ Other: ______________________________
please specify

INTERNAL CONSTITUTION

4. Please provide the following information regarding the membership of your board: (Please print or type.)

Name	Occupation	Sex	Approximate Age	Racial-Ethnic Background*	Developmentally Disabled?**	Relationship to Develop. Disabled person.***	Phone
(Chairman)							

* Enter the proper number: 1. Black -- 2. White -- 3. American Indian -- 4. Latin -- 5. Asian-American -- 6. Other.

** Enter the proper letter: Y = Yes; N = No.

*** Enter the proper number: 1. Parent -- 2. Sibling -- 3. Aunt or Uncle -- 4. Other -- 5. None.

BOARD QUESTIONNAIRE

-II-

BUDGET

1. Who allocates funds directly to your board? (check all that apply -- indicate approximate/exact (circle one) percentage from which source -- name agency(ies)).

___ Federal Agency(ies): ___% a) ___________
name(s)
b) ___________
c) ___________

___ State Agency(ies): ___% a) ___________
b) ___________
c) ___________

___ Private Foundations: ___% a) ___________
b) ___________
c) ___________

___ Other: ___% a) ___________
b) ___________
c) ___________

2. Who audits the expenditure of funds that the board has allocated to local community agencies?

Name	Title	Agency

3. What legislative and outside administrative sources have been of most assistance to the board? (check all that apply -- circle those that have been most helpful.)

__ Wisconsin Statutes

__ Wisconsin Administrative Code

__ The State Plan for the Developmental Disabilities Act.

__ U.S. Code

__ Code of Federal Regulations

__ County Corporation Counsel

__ Area-wide Comprehensive Health Planning Agency ("B" Board)

__ Division of Health Policy and Planning

__ 51.42 Board

__ 51.437 Board

__ Developmental Disabilities Board

__ Department of Public Instruction

__ Division of Mental Health

__ Division of Vocational Rehabilitation

__ Division of Family Services

__ Other: ______________________________________
please indicate

____

4. What percentage and/or amount of your funds during fiscal year '74 (i.e., 7/1/74 - 6/30/75) and fiscal year '75 (i.e., 7/1/75 - 6/30/76) have been allocated for each of the service areas indicated below:

Service Areas	Past Fiscal Year %	and/or $	Present Fiscal Year %	and/or $
1. Evaluation:				
2. Diagnosis:				
3. Treatment:				
4. Day Care:				
5. Training:				
6. Education:				
7. Sheltered Employment:				
8. Personal Care:				
9. Domiciliary Care:				
10. Special Living Arrangements:				
11. Information and Referral:				
12. Counseling:				
13. Follow-along:				
14. Protective:				
15. Recreation:				
16. Transportation:				

5. How do members of your board achieve membership? (check one and complete response)

__ Elected -- By Whom: ______________________

__ Appointed -- By Whom: ______________________

__ Other: ______________________

BOARD QUESTIONNAIRE

-III-

CONTACT WITH OTHER AGENCIES, BOARDS, ETC.

1. Is there a 51.42/51.437 Board in your area of jurisdiction? (check one -- if no, proceed to question 2).

__ Yes, __ No.

If Yes: Do you communicate with this Board? (check one)

__ Weekly

__ Monthly

__ Approximately once every six months

__ Other: ____________________

1.1 Please explain the benefits or problems which occrue to your area of jurisdiction as a result of having two boards with overlapping statutory responsibilities?

Benefits	Problems

2. If a recipient of a service for which you are responsible has a problem which you cannot solve within the board, to whom do you go for advice? (check all that apply -- if more than one, circle the one used most frequencly.)

__ County Corporation Counsel

__ Area-wide Comprehensive Health Planning Agency ("B" Board)

__ 51.42 Board

__ 51.437 Board

__ Developmental Disabilities Board

__ Department of Public Instruction

__ Division of Mental Health

__ Division of Vocational Rehabilitation

__ Division of Family Services

__ Other: ____________________

____

____

3. What agencies do you regulate? (Please check and attach a list if the space provided is not adequate.)

__ All the agencies which you fund.

__ Other: ______________________________

____

3.1 How do you evaluate the quality of the services these agencies perform? (check all that apply.)

__ Verbal reports

__ Written reports

__ Scheduled on-site visits

__ Unscheduled on-site visit

__ Investigation of client complaints

__ Outside evaluator

__ Other: ______________________________
please specify

3.2 How often do you evaluate these agencies? (check all that apply.)

__ Monthly

__ Quarterly

__ Semi-annually

__ Annually

__ Other: ______________________________

4. What agency is primarily responsible for regulating your board?

____

4.1 How does this agency evaluate your board?

____

____

____

4.2 How often are you evaluated by this agency? (check all that apply.)

__ Monthly

__ Quarterly

__ Semi-annually

__ Annually

__ Other: ______________________________

5. List any agencies serving developmentally disabled citizens in your geographic area of jurisdiction which you do not regulate.

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

BOARD QUESTIONNAIRE

-IV-

ADVOCACY

1. Define advocacy as you perceive it.

Uncertain: _____

2. If your board has ever expressed its perception of advocacy, please describe it.

3. What do you see as the goals of advocacy services with developmentally disabled clients?

Uncertain: _____

4. What do you see as the differences between advocacy and protective services?

Uncertain: _____

5. In which of the sixteen service categories do you think advocacy services are most needed? (check all that apply -- circle "most needed" category.)

Diagnosis: _____

Evaluation: _____

Treatment: _____

Personal Care: _____

Day Care: _____

Domiciliary Care: _____

Special Living Arrangements: _____

Training: _____

Education: _____

Follow-along: _____

Sheltered Employment: _____

Recreation: _____

Counseling: _____

Protective Sociolegal: _____

Information Referral: _____

Transportation: _____

6. In addition to the above sixteen service categories, in what other problem areas are advocacy services needed for the developmentally disabled?

____

____

____

Uncertain: _____

7. Which of the developmentally disabled client groups do you think are most in need of advocacy services? (check all that apply -- circle group most in need.)

_____ Cerebral Palsy (specify age group: _____)

_____ Mentally retarded (specify age group: _____)

_____ Epileptics (specify age group: _____)

_____ **Multiple impairment (specify age group: _____)**

_____ Others (specify age group: _____)

_____ None of above groups (reasons given: ____________________

____)

8. Briefly describe what you believe to be the optimum administrative location and funding source for advocacy programs.

____

____

____

Uncertain: _____

9. Have you received information concerning outside agencies willing to fund advocacy efforts? (check one.)

__ Yes __ No.

If you have received information concerning such agencies willing to fund advocacy efforts, which ones are you familiar with? (please list.)

____

____

____

10. What agencies, groups or individuals do you know of, which perform advocacy services for developmentally disabled clients in your geographical area of jurisdiction? (please list names, addresses, etc. if possible. Attach list if space provided is not adequate.)

a. ____

b. ____

c. ____

d. ____

Uncertain: _____

11. What other groups, boards, agencies (local, regional and state) do you think will be cooperative/facilitative in initiating advocacy services? (please list and state how these might be cooperative/facilitative.)

____

____

____

Uncertain: _____

12. Do you currently regulate/fund any advocacy programs?

__ Yes __ No.

If Yes, answer questions 15 through 19.

If No, answer questions 13 through 19.

13. If you and your board were to initiate advocacy services, briefly describe what you believe to be the optimum administrative location and funding source for such programs under your jurisdiction.

____

____

____

Uncertain: _____

14. What problems do you face if you were to initiate such advocacy services? (administrative, personnel, financial, etc.)

____

____

____

Uncertain: _____

15. What is the source of those funds for your advocacy programs?

____

____

____

16. How does your board ensure that services to developmentally disabled citizens served by agencies are the "least possible restrictive" on their personal liberties?

____

____

____

17. How often did developmentally disabled clients or their representatives present the board with a grievance during the past twelve months? (check one and indicate number.)

__ Exactly: _____

__ Approximately: _____

18. What are the most common types of developmentally disabled client grievances that come to your board?

a. ____

b. ____

c. ____

19. If your board is unable to resolve a grievance from developmentally disabled clients or their representatives, what do you do?

____

____

____

____

APPENDIX I

DOCUMENTS

1. Are minutes/transcripts kept of board meetings: (check one)

   ___ Yes; ___ No.

   If Yes: Please send us copies of those documents pertaining to the last two meetings.

2. Please enclose a copy of your by-laws and operating procedures (including any client grievance procedures) with this completed questionnaire. If these are not available, please describe the board's responsibility and authority.

   ____

   ____

   ____

3. Please send us a copy of the last fiscal year's allocation if available. If it is not abailable, to whom does your board allocate funds? (Please indicate name of agency and percentage of total allocated and/or amount for each agency -- attach a list if space provided is not adequate.)

   1. ______________________ $ ________ and/or ________ %
   2. ______________________ $ ________ and/or ________ %
   3. ______________________ $ ________ and/or ________ %
   4. ______________________ $ ________ and/or ________ %
   5. ______________________ $ ________ and/or ________ %

4. If you have documents regarding funding criteria, priority areas, standards for acceptance or rejection of requests for funds, etc., please enclose them with this questionnaire. If not, please describe such criteria below:

   ____

   ____

   ____

   ____

5. Please enclose a copy of the criteria which you use to evaluate agencies. If this is not available, please explain below:

____

____

____

6. If you are required to conform to a formal reporting mechanism, please enclose a copy of themost recent report(s) which you submitted.

js
8-14-75